

**TO INVESTIGATE THE EMOTIONAL IMPACT
OF SIBLING
BONE MARROW DONATION**

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ABSTRACT

This thesis reports on a study of the emotional impact on sibling bone marrow donors. It considers in particular donation that takes place during their adolescence and was prompted by the concern of medical and nursing colleagues managing the treatment of young people with cancer. The study interviewed five donors and discusses these interviews using the lens of psychoanalytic theory to offer a deeper understanding of these donors' experiences.

Understood in this way, particularly using the psychoanalytic concept of projective identification, a main finding of the study is that whilst these donors would not have refused to donate, based on the love and duty of a filial relationship, the donation evoked complex emotions arising from the sense of the physiological merging of two people.

The study makes some recommendations to change current practice within the hospital where I work in order to improve the psychological management and care of sibling bone marrow donors.

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INTRODUCTION

This thesis addresses the question of what is the emotional impact on siblings who donate stem cells found within their bone marrow to a brother or sister. The study focuses on adolescent sibling bone marrow donors between the ages of thirteen and eighteen years. The following chapters describe how I have researched this, drawing on my core training as a child and adolescent psychotherapist in a teenage and young adult psycho-oncology team. I report on what the donors interviewed had to say about their experience, how I have understood this, and the recommendations I have made on the basis of this understanding.

In 2009, a consultant haematologist at the large London hospital where I work asked me to join her in one of her clinics, as she was concerned about the emotional impact on some of the adolescent bone marrow donors who were donating to a sibling. The Human Tissue Authority (HTA) was also preparing to register a bank of professionals who could assess sibling donors under the age of 18 in order to protect them from undue pressure or possible coercion from anxious relatives. There was therefore a growing concern at that time to think about how to support sibling donors, not only in relation to their decision to donate or not, but throughout the donation process. This began a journey for me into previously unknown territory, as I endeavoured to understand not only the medical implications of donation but also the emotional impact on this group of donors, who were not only a match medically but were also matched by their family bonds.

In this clinic I met a woman aged 16 who was about to donate bone marrow for the second time. She was quiet and outwardly seemed happy to donate again. She mentioned quietly during the medical examination that she felt she had shrunk since donating. The fact that she was a little anaemic was identified by her blood tests, and she was prescribed iron. The consultant haematologist confirmed that she had not physically shrunk, and her concerns about her height were attributed to her feeling tired. I did not at that point explore her worry any further. Later that day, when she came to begin her second donation, this young woman had a panic attack, and staff asked me to talk with her. Her

words about shrinking came back to me, and I asked her to tell me more about this worry. I return to this below.

In April 2013 I attended a lecture given by Dr Galen E. Switzer, clinical psychologist for the Anthony Nolan Trust (Switzer 2013). Switzer described the process of recruiting unrelated adult donors in the USA. He explained that after an initial recruitment drive in local churches and clubs, the recruiters would sign up many willing volunteers. Many of these potential participants would withdraw their consent when a request was made some months later. One possible explanation was that the time lapse allowed volunteers to think more and allowed anxieties to arise. Switzer suggested in his presentation that one of these anxieties might have been the fear of 'contamination'. By this he meant an anxiety that giving a part of one's physical self implied a real physical link with that patient that would mean not just shared blood or bone marrow, but a shared disease.

It is easy to be dismissive of these anxieties. But a psychoanalytic perspective is helpful here, and opens up the possibility to think more intimately about the role of an internal world, human fears and fantasies. I will address this aspect of bone marrow donation in this work, in particular linking it to sibling relationships.

The young woman previously mentioned spoke with me about her fears, and seemed relieved that they were heard and understood. She went ahead with the donation, not I think because of our discussion – although it did appear to be helpful – but out of love for her brother. A key question, however, is how easy it would have been for her, or any sibling donor, to refuse. This is a powerful question. In 13 years of working full-time in paediatric oncology, I have met only one sibling who was so anxious that she visibly withdrew when requested to give a blood sample. This person physically drew her hands and arms up into the sleeves of her jumper, as though even the thought of a blood test was terrifying. I have also seen siblings weep with grief that they were not a match; one of them felt that his brother would not have died if he had been able to offer his bone marrow.

The haematology consultant was right in her sense that we need to think more about the experiences of sibling donors, and I will be grateful always for her

thoughtfulness. I am hopeful that this piece of research will go some way to shed light on what may be required for this group of sibling donors.

In 2007 I became an accredited assessor (AA) for the HTA. This was in line with the principles of the Human Tissue Act 2004. This Act set out a new legal framework for 'the storage and use of human organs and tissue from the living and for the removal, storage and use of human organs and tissue from the deceased' (HTA Regulations 2006:2). There were six topics covered by the code of practice, including 'donation of allogeneic bone marrow and peripheral blood stem cells from transplantation'. From April 2006 the HTA was the competent authority for the UK under the EU Tissues and Cells Directive for regulating human tissue banking for transplantation purposes. Previously the assessments and approvals were made locally by the transplant team for the donation of bone marrow and peripheral blood stem cells from children, or from adults who lacked capacity. (The Mental Capacity Act 2005 describes 'capacity' as the ability to understand information, make a decision and then communicate clearly any decision made.)

In general this continued to be the case. However, the appointment of an AA for every transplant became compulsory and meant that there was some protection for this group of would-be donors. Decisions were made according to the principles and procedures in the HTA's code of practice. The Human Tissue Act 2004 requires that potential sibling donors under the age of 18 be assessed for competency under the Gillick competency guidelines. This means that a child from the age of 13 upwards can make a decision about medical treatment which is in their best interests, providing they understand what is being proposed. It is the AA's job to make sure that the young person understands what donation entails, and that there is no evidence of coercion or bribery. The decision must be written up, signed and attached to the donor's file. These declarations must be available to the HTA on request.

Thus my connection with the senior clinician and bone marrow transplant team grew and developed. I continued to wonder how difficult it might be for a sibling to decline to donate. I was often moved by the determination and bravery of the siblings I had to assess. One asked me if she would walk again after having marrow removed from her pelvis. She had not dared to ask during the medical

discussions, but had continued to insist that she was keen to donate, feeling that it was the only chance for her brother to survive. Whilst I was able to allay her fears about any impact on her mobility, I was deeply moved by her preparedness to sacrifice so much for her sibling. I began to ask all the donors if there were questions that they had not dared to ask. I also began to state the truth that should their sibling not survive, it would not be the failure of the donation, but would be because the disease had been too strong. I asked one young sibling who was anxious about needles what she would say if I said that she should not donate, and she replied rather crossly 'I would do it anyway.' It became increasingly clear to me that donation was not a simple medical procedure. In discussion with the bone marrow transplant team, and after some discussion with another local AA, I began to draw up a proposal for research into the emotional impact on adolescent sibling bone marrow donors.

My training as a child and adolescent psychotherapist has of course influenced my choice of how to research the emotional impact on an adolescent sibling donor. I had read several accounts that siblings of children with long-term illnesses such as cancer and sickle-cell anaemia show a threefold increase in behavioural difficulties and post-traumatic stress symptoms such as shock, fear, sadness and anger (Sharpe and Rossiter 2002; Hinds et al. 2012; Alderfer et al. 2010), but there was little in the literature about the specific emotional impact on a sibling donor of having donated.

I have described my role as assessor of under-18-year-old sibling donors, and it was from this work that I began to want to understand in more detail what it was like to donate to a sibling. What were the questions I had to ask? These ranged initially from their immediate anxieties regarding the medical procedure to whether they felt that donating had altered their relationship with their sibling. I read fictional accounts of sibling relationships: one by Jodi Picoult (2004) in relation to sibling donation, and a novel by Kazuo Ishiguro (2005). Ishiguro described the lives of human clones, and vividly conveyed how fantasy plays an active part in our lives. How might such fantasies contribute to the emotional impact of becoming a sibling bone marrow donor? How could I gather a more in-depth understanding of what donation to a sibling meant? Did the sibling relationship alter for better or for worse? Did donors feel like 'spare parts' and that they might eventually be 'used up', especially if further bone marrow was

needed? Did sibling donors feel that they could not 'make a fuss' about blood tests or donation as their sibling was undergoing the much greater challenge of a transplant? These were all preoccupations and anxieties that had been expressed to me in my clinical work, as I illustrate in the following vignette.

In my role as assessor I had to interview a young man of 14 who was to be a bone marrow donor for his father. This is unusual, as the chances of a match will only ever be 50/50 in parent-child cases. In this case, because of the ethnicity of the patient, it had been impossible to find an unrelated donor. A complication was that the man's sister, who lived some distance away, was a 100% match, but having been tested she had refused to donate because she was too anxious about the procedure. Nothing the medical team could say would change her decision. The patient desperately needed a transplant, and hence there was a decision to invite his son to donate. The boy was very concerned about his father, but also fearful of coming to hospital for a general aesthetic. He spoke to me in the interview of his graphic dreams of snake attacks, robberies and muggings. We talked about these dreams and agreed that perhaps he did feel as if something might be taken from him by force. However, he also understood that he had some conflicted feelings about his aunt, who perhaps unintentionally had put him in this difficult position. His dreams of an attack seemed to connect to both the removal of bone marrow and also the possible loss of his father and the guilt that might follow. However, we agreed that my preventing him from donating would also be like a violent attack on him – denying him the possibility of saving his father.

This brought me back to my questions. How difficult would it be to refuse to be tested? Once tested and found to be a suitable donor, could one then refuse because of one's own fears of the medical procedure? What happened for sibling donors if they were a 100% match: could they still find it possible to refuse to donate? And what if their brother or sister died despite the donation?

I wanted to try to understand what seemed to me to be huge questions and huge responsibilities for siblings, alongside perhaps many weeks and months of a sibling being ill and requiring a great deal of attention. As I mentioned above, I have only known one sibling refuse, but I have also met a few siblings who were distressed at not being a match.

The HTA put in place checks and assessments with the intention of preventing coercion or bribery. However, I was interested in the internal emotional world of the donor, to try to understand what powerful emotional forces were at work within donors that might make a straightforward assessment more complex.

So I embarked on the research that is to follow with my question: what is the emotional impact of donation on an adolescent sibling bone marrow donor? My first chapter explains the medical side of a bone marrow donation. This was guided by my medical colleagues, and its purpose is to introduce the reader to some of the terminology used in the procedure.

In Chapter Two I review the literature connected to sibling bone marrow transplants, and also literature regarding the sibling relationship and all its complexity. I include relevant psychoanalytic literature and theory, since this is the bedrock of my training. In Chapter Three I discuss the methodology I used, and also chart my learning in relation to research, an area which was new to me.

Chapter Four presents and analyses the data from each of the five donors' interviews. In Chapter Five, the discussion, I explore the findings and their relation to the literature.

Finally, in Chapter Six I make recommendations on the basis of what I learnt from the research, and conclude what has been an extraordinary journey for me in both discovery and learning.

CHAPTER ONE:

MEDICAL BACKGROUND TO BONE MARROW DONATION

It is important in this work for readers with no medical background to have insight into the reasons for bone marrow or stem cell transplantation, as it may help them to understand something of what the families are confronted with in the journey to find a cure for their child's disease.

The explanations will of course be simple, as I do not have a medical background. However, it has been guided and approved by my medical colleagues in the transplant team.

1.1 Brief history of bone marrow transplant treatments

Bone marrow transplantation has evolved over a period of about 50 years. The impact of nuclear warfare stimulated interest in the effects of radiation on the human body. Bone marrow, which was sensitive to the lethal effects of radiation, could be successfully rescued by a reinfusion of marrow cells. The first successful transplant was performed by Dr E. Donnell Thomas in Cooperstown, New York in the late 1950s. Initially success was limited, and the procedure was only performed using identical twins, as this reduced the risk of problems related to graft-versus-host disease (GvHD). GvHD occurs when the transplanted cells (the graft) attack the patient (the host) as they would a foreign object or infection. In 1975 Thomas moved his research to the Fred Hutchinson Cancer Research Center, where much of the developmental work on bone marrow and blood stem cell transplantation has been done. He received the Nobel Prize in medicine in 1990 along with Dr Joseph E. Murray, who pioneered kidney transplantation.

It was not until 1968 that the first non-twin bone marrow transplant took place, and then in 1973 the first successful non-related donor transplant took place in New York. In 1973 Shirley Nolan established a register of potential bone marrow donors in honour of her young son, who had died from a condition that might have been cured had a suitable match been found.

At the time of writing, bone marrow transplants are more commonplace, with about 20,000 a year performed for people aged 0–74 in England. I would also

like to point out that I am writing from the perspective of an adolescent service. The treatment of teenagers and young adults varies from that given to full-grown adults.

1.2 Medical information

The phrase 'bone marrow transplant' has generally been replaced by 'stem cell transplantation'. However, in this research I shall always refer to this treatment as a bone marrow transplant. Any transplant in which the stem cells come from a matched donor is called an allogeneic transplant.

In the centre of many bones is a spongy material called bone marrow, and within this marrow are tiny honeycomb niches where the haematopoietic stem cells capable of creating all other new blood cells live. Fewer than one in 5,000 cells is of this type, but these cells are versatile enough not only to reproduce themselves, but also to create the other three types of cell required by the body:

1. Red cells, which contain a protein – haemoglobin – which carries oxygen around the body, but which will cause anaemia when insufficient numbers exist.
2. White cells, of which there are two main types: neutrophils and lymphocytes. Acting together, they fight bacteria, viruses, fungi and parasites. Broadly speaking, neutrophils give general protection against infection, while lymphocytes are responsible for the production of antibodies. These cells have the ability to recognise 'foreign' cells and to trigger a response from the immune system. Some lymphocytes can live for years, but others only for hours.
3. Platelets, which continuously circulate the body in the blood and are responsible for the creation of clots to prevent bleeding if an injury is sustained.

The stem cells in a healthy adult must produce three million red blood cells and 120,000 white cells every second. When this normal production system is affected by a disease such as leukaemia, the bone marrow cannot function normally. Chemotherapy and/or radiotherapy are used to treat these conditions, often with great success. But in some cases the underlying disease is too aggressive or has returned, and the only way to ensure a lasting cure is to

undertake a bone marrow transplant. This is when stem cells are taken from a donor who is a genetic match and are transplanted into the patient. In cases where there is a good match with the patient, the medical team may decide to take this option sooner in the treatment journey, rather than subject the patient to several courses of chemotherapy. Chemotherapy, whilst vital in most cancer treatments, inevitably weakens a patient, so that eventually a bone marrow transplant can prove to be the only curative option.

Any transplant using stem cells derived from someone other than the patient is called an allogeneic transplant. The human body is able to distinguish between its own and 'foreign' cells thanks to a protein (or antigen) on the surface of the white cells known as human leukocyte antigen (HLA). HLA is part of an individual's genetic characteristics. It is similar to blood group, but more complex and diverse. The better the match, the better chance the new cells will be accepted by the patient, and it will be less likely that the patient will develop problems with the transplant. Therefore a fully matched sibling donor is the first choice donor for patients.

Each child in a family has a 25% chance of being a full match (10/10 match) with a sibling, a 25% chance of being no match and a 50% chance of being a half match. A 10/10 sibling match is likely to match not only in the six main markers required but also in minor tissue type markers, which is why a sibling donor who is a match offers a better chance of survival for the patient.

Transplantation offers a cure to many, but not without life-threatening risks, and not all transplants are successful. One significant complication is GvHD, described above. GvHD can range from mild to severe. It can appear very soon after the transplant (within 100 days) and be acute, or can appear later and be classified as chronic. It may cause gut, skin and liver complications, which in many cases can be treated but in others may become life threatening. Ironically however, GvHD does provide one important advantage which is a key benefit of donor transplants: the graft from the donor cells will attack any residual cancer cells and create a graft-versus-leukaemia effect to keep disease in remission in the long term. Managing and moderating these two aspects is one of the most delicate and carefully monitored parts of the transplant process. Many patients who undergo a bone marrow transplant will have been ill for some time. They

may well have endured months of chemotherapy, and are often in a weakened physical state. This may make the transplant challenging both physically and psychologically. In particular, the strain can be immense if this is the patient's last hope of a cure.

However, transplantation is not the sole preserve of those who have malignant diseases. It is now offered on a more frequent basis to patients suffering from conditions such as aplastic anaemia, auto-immune conditions such as chronic granulomatous disease (CGD), or immunodeficiencies that render the patient more susceptible to infection. In much the same way as cancer, this sort of illness causes disruption to schooling and requires numerous visits to hospital. This in turn can leave the patient fatigued and result in a poor quality of life. Stem cell transplantation can be the only cure and only route back to a normal life.

1.3 Bone marrow collection

In order to collect haematopoietic stem cells from a donor, there are two different methods, and both are routinely and successfully used throughout the world. The most common method is to give the donor a four-day course before collection of a growth factor called granulocyte colony stimulating factor (G-CSF) by injection. This chemical stimulates the production of extra stem cells in the marrow and allows some of them to spill out into the circulating bloodstream. This can create mild flu-like aching in the donor's bones and joints, although some donors describe more unpleasant pain and side effects such as nausea. On day five the donor is connected to a cell-separating machine, which pulls the blood through a centrifuge and collects only a specific quantity of white blood cells and stem cells, returning the rest of the blood to the donor, during a period of about five hours. Apart from mild tingling caused by the anticoagulant used to prevent the blood clotting in the machine, the donor should be comfortable throughout. The cells that have been collected go into a blood bag, and are given to the recipient via a drip in the same way that they would receive a blood transfusion. This is done as soon as possible to ensure that the maximum number of cells survives. Sometimes the donor will need to repeat the donation the following day if the number of cells collected is insufficient for the transplant.

This method of collection, known as peripheral stem cell collection, is now the most commonly used and accounts for 90% of transplants.

The alternative method to collect donor cells is the traditional bone marrow harvest. Donors do not then need to have G-CSF injections. This method involves the donor having a general anaesthetic. Once asleep, they are turned onto their stomach on the operating table and a tiny hole is made in the skin just over the iliac crests of each hipbone. Then a rigid bone marrow harvesting needle is inserted into the bone itself, and a syringe is used in that narrow space to aspirate a predetermined amount of marrow up to 1,500 millilitres. This is put into a sterile blood bag. This method is suitable for conditions where the higher incidence of white cells produced by G-CSF is not needed to fight malignant disease, for example with aplastic anaemia. Donations taken from very young children also use this method.

Side effects from this method include back pain and tiredness for about a week following donation, but the stem cells and blood removed are rapidly reproduced. It also involves the donor staying in hospital for two nights.

1.4 Bone marrow donation

The recipient in the meantime will have completed their conditioning treatment. They will have had intensive chemotherapy to kill off their disease, and in some cases will have had total body irradiation to destroy their own marrow and create space for the incoming cells. This will leave them highly vulnerable to infection, as their own immune system will have been destroyed. The recipient will be given drugs to prevent the new immune system from attacking their body. This can be a difficult and frightening time for them and their families.

The collected cells are infused into the recipient in the same way they would receive a blood transfusion, via a drip. Some recipients will have a reaction to the procedure and will require medication to reduce the impact. The family, including the sibling donor, are often present to watch the cells going in, and it can be an emotional time for everyone.

The recipient will be monitored very closely for the weeks following the donation. They will be checked every day for signs that the new cells have started creating blood. It can take up to three weeks for the first signs of activity

and for the new cells to 'engraft'. It can take one to two years post-transplant for the new immune system to be fully functioning. The disruption to the lives of both the recipient and their family is huge, physically and emotionally. Inevitably some recipients will take much longer to recover than others. They may have to endure multiple readmissions to hospital and many clinic visits before they can resume a more normal life again. The need for a second or third transplant occurs when the new cells do not engraft fully, and this can happen at any stage in the first few months after transplant.

1.5 Conclusion

This is a simple explanation of a complex procedure, but I hope it provides the reader with a picture of the landscape through which donors travel.

In the introduction I referred to the HTA and its request in 2004 that donors under the age of 18 be assessed to see whether undue pressure has been used to get them to be tested and to donate. Assessors are trained to do this and report their findings to the HTA, which decides whether the donation from the sibling should go ahead, whether further support is required, or indeed whether an unrelated donor needs to be found. According to new guidance, the medical team working with the patient must assess possible sibling donors over the age of 13 for capacity. They then refer that sibling donor to the AA, who must meet with that young person to ensure that they understand what they are offering, that no bribe (however small) has been offered or given to either the child or the parent, and that there has been no coercion. Thought must be given to the best interests of the donor and whether the donation might cause undue distress or difficulty. It is a criminal offence to remove living human tissue from another person without their informed consent. In the case of young children or adults who do not have capacity, the decision must be made by those with parental rights or guardianship, with the best interests of the sibling donor at heart.

The task of assessing potential sibling donors is a difficult and often humbling one. Young siblings who have been told what donation involves will say that despite their anxiety they cannot refuse. Although I rarely have the legal task of assessing siblings for donation, since almost all siblings in our adolescent and young adult work have capacity, I always meet these young people alone in

order that they have the chance to express any fears, or to ask that question that may have felt too foolish to mention – for example, ‘will I be able to have children once I have donated?’ One sibling donor said his sister was having injections every day, so how could he possibly complain about a brief period of injections to boost his bone marrow? Others expressed the fear that if their sibling died it might be their fault.

In the next chapter I shall review the literature on sibling bone marrow donation. I will also include psychoanalytic literature and more general psychological literature regarding the complexity of sibling relationships, as it is clear from siblings’ comments like those mentioned above that the act of donating bone marrow is complex in many different ways.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

2.1.1 Search strategy

The identification of literature to support this review was conducted in three stages. First, I gathered literature through a search using Google Scholar. I used the search terms ‘sibling bone marrow donor’, ‘adolescent sibling bone marrow donor’ and ‘paediatric bone marrow donor’. In addition to the literature emerging from this search, my medical colleagues in the haematology team gave me some papers, including Weaver et al. (2015). There were a number of papers in this subject area and they were cross-disciplinary in theoretical orientation, drawing on evidence of the impact of donation from both medical literature and developmental psychology. There were four papers on bone marrow donation that included psychoanalytic ideas: Henningsen (1980), Pot-Mees (1987, 1989) and Daune (2014). This first, partly idiosyncratic gathering of material provided a starting point for the review.

Next, I undertook much more systematic searches for research on the impact of donation, using medical, psychological and psychoanalytic databases. Here I used combinations of search items comprising ‘sibling bone marrow donation’ and ‘impact of cancer or serious illness on siblings’. Broad search criteria were donation in adolescence with an age range of 12–18, the impact of bone marrow donation, and the impact of kidney donation.

In these two stages, there was systematic searching which was complemented by a more intuitive approach, checking papers’ reference lists to identify further possible sources and lines of enquiry that reported either original research or papers that sought to verify or contest prior research.

In the third stage, my attendance at national and international conferences and seminars led to the identification of a small number of sources and lines of research not identified in the first two stages. A good example of this occurred through my participation in the 2017 European Bone Marrow Transplant conference, where I met Alice Polomeni, a clinical psychologist working in Paris.

Polomeni spoke of the ‘fantasy of incest and twinning’ in her work with adult patients receiving a sibling donation. She also introduced me to the work of Nicole Alby (1990), which demonstrates that one impact on donor recipients is the feeling of being taken over by the donor.

2.1.2 Structure

In the first part of the review I will discuss the psychoanalytic literature as it relates to individual development and the development of the sibling relationship. In part two I will also refer to key insights from more general psychological literature about siblings, and also touch on ideas from two works of fiction that are especially relevant to this study. I believe this literature offers further insight into our fantasies and feelings about our ordinary human interactions through the liveliness and richly distinctive descriptions of novelists, which demonstrate the vibrancy of human relationships.

In the second part of the review I will look at the research literature on sibling bone marrow donation, mainly in the adolescent years. This includes research on the psychological impact on recipients as well as the impact of a sibling’s illness on brothers and sisters.

2.2 The sibling relationship

2.2.1 Richness and mystery

‘The nature of sibling relationships in all their complex forms of love and hate still remains more of a mystery than the passions and developmental vicissitudes of the parent-child relationships’ (Sharpe and Rosenblatt 1994:491). This quotation seems to encapsulate much of what I want to explore. I will look at how psychoanalytic writing has explored the ‘complex forms of love and hate’ in sibling relationships that Sharpe and Rosenblatt refer to as a ‘mystery’.

Anna Freud was able to observe the children in the Hampstead Nurseries (1942–1943). Pretorius (2014:64) describes how Freud highlighted observations in connection with sibling relationships: Freud ‘traces the development from the infant’s selfish outlook on the object world, through cooperation with peers, to companionship and a capacity for ambivalence’. Freud’s observations at the Hampstead Nurseries enabled her to continue the

thinking about child development which she had begun in her nursery in Vienna. These studies had been interrupted by the Nazi government and the persecution of the Jewish people. Freud (1965) had written a 'developmental line', where she described the way she saw a child's inner life growing and changing, to be used by trained observers to help think about the child's development. There were four stages. First the child only views the world and those in it in a narcissistic way; other children might be the causes of parental distraction. In the second stage children view other children as objects similar to toys. In the third stage there is a sense that they can be used to help in play. In the final stage they regard them not only as rivals but perhaps also as partners.

Freudian theory holds that our unconscious contains many experiences and figures from throughout our lives, which may include the arrival of a sibling. This is important in our understanding of the unconscious relationship that may exist between brothers and sisters as well the relationship that is conscious. This is emphasised by Hindle and Sherwin White (2014:167): 'in our opinion, the sibling dimension, its impact on development, and the additional process of separation and individuation, not only from parents, but also in relation to siblings, can go unrecognized and be underestimated and needs further attention.' Rustin (2007: 34) describes the importance of siblings and 'quasi-siblings (cousins for example)' as a precious resource: 'Our brothers and sisters are persons of value to us in their own right and are not only competitors for parental love.'

However, in the early days after the birth of a sibling this 'resource' may not be recognised, and instead a sibling may be felt as a rival for parental affection. Mitchell (2003:xi) for example suggests: 'When a sibling is in the offing, the danger is that the hero – "His Majesty the Baby" – will be annihilated.' Mitchell's (2003:41) overriding view of sibling relations is that they are based 'first and foremost on hatred, not envy'. She goes on to say that this hatred may change to envy and involve some competitiveness, but that essentially siblings do not need to repair these destructive feelings towards each other in the way that Melanie Klein (1988a) suggests an infant must do with the mother. Further, Mitchell suggests that gratitude does not need to play a part in the relationship, as it must with the mother who provides the food.

Mitchell also suggests that the Oedipus complex works laterally, not just vertically as proposed by Sigmund Freud. Mitchell (2003:41) believes that children's Oedipal desires for their parents include a reproductive fantasy, but that this is not so with masturbatory fantasy about a sibling. Mitchell is addressing the psychoanalytic theory that most children in fantasy desire to have a baby with either mummy or daddy, but she is also stating her belief that this is not so with their sibling sexual fantasies. She believes that the feelings in relation to a sibling are more linked to exploration, experimentation and pleasure, not procreation. This thinking is supported by Parens (1988:49): 'This idea is supported by the following direct observational finding: given that siblings, especially older ones, become libidinal objects from so early on makes the strong likelihood that they are emotionally invested autonomously.' Parens is noting that children may form rather sensuous relationships with their infant brothers' or sisters' bodies and that this happens most naturally, almost as though it is a part of their explorations of the world.

Bank and Kahn (1982) also suggest that sibling interaction is more concerned with exploration rather than procreation. They acknowledge that most siblings will display 'playful curiosity' (Bank and Kahn 1982:155), and that by the ages of four or five they will be aware of the difference between girls and boys. Their games may include 'mummies and daddies' and 'doctors and nurses', allowing them further exploration of each other's bodies. I will return later in the chapter to the theme of curiosity and exploration, but will do so in relation to sexuality – an important theme for adolescents – as it has an important bearing of the topic of bone marrow donation.

Envy, jealousy or rivalry, rather than sexual feelings, are a part of the sibling relationship that has been written about by a number of authors. Mitchell (2003:80) writes of the first sibling question: 'where does the baby come from? To which I emphatically add – or even place first – where does that leave me?' Rowe (2007:56) takes a similar line of argument: 'Whatever their age, all children are displaced when a new sibling is born, and this displacement is felt immediately as the threat of being annihilated as a person.' This describes some of the more passionate emotions of any child who feels they are no longer the only focus of their parent's attention.

Neubauer (1982), in keeping with Mitchell's argument about the arousal of hate, writes about his belief that the arrival of a new sibling increases the aggressive drive of the older child. This aggression can be managed by thoughtful parents, and the older child can learn from the experience. Neubauer (1982:1) also reminds us of the original meaning of the word 'rivalry', which I find descriptive and helpful: 'One dwelling by or using the same stream as another or fighting for the access to the river'. This links in my mind to the source of life, the mother, and a child's need to remain connected to her, her breast and the source of life-giving nourishment. It adds to our understanding of the child's reactions when a new baby is born, and their sense of perhaps losing 'access' to the mother.

Dunn (1984), echoing Neubauer's suggestion, found that parents who engaged children in the care of the new baby and who spoke of that baby's feelings nurtured a closer relationship between their children. She found that siblings whose parents included them in discussions about the baby helped the child maintain a more friendly view of the baby: 'Even as young as two years, children are interested in and reflect upon the feelings and wishes of their siblings, and mothers who encourage this concern are helping the growth of a loving relationship' (Dunn 1984:87–88). Coles (2014:9) adheres to this view and suggests a balance can be found: 'In a good enough environment, siblings love and hate each other in good measure.' Fonagy (2001) and Fagan (2014) also support the view that secure parent-child relationships promote better sibling relationships. Coles (2003:81) is clear that rivalry and jealousy are 'not the fundamental bedrock of sibling experience. They are just a part of it.' An important part therefore of the sibling relationship is not just rivalry but something more complex – a mix of hate and love.

2.2.2 The sibling bond

The word 'bond' can be understood in this sibling relation context as a powerful emotion that binds or even shackles, as well as conveying a sense of emotional connection between two people. As seen in the literature above, this dual meaning is the challenge for many siblings, with loyalty binding them together, both in love and at times in hate.

Cicirelli (1995) looks at the sibling relationship as it evolves over the siblings' lifetime, and notes that it is normally the longest-lasting relationship, as generally children will outlive their parents. Cicirelli notes the importance of this relationship as one where in most cases children and adolescents share the intimacy of everyday life during their formative years. Whilst the relationship will change when children leave home, those connections will often remain an important part of their adult life. This shared experience, which is an essential part of the sibling relationship, was looked at by Gass et al. (2007) over a period of two years. They found that sibling relationships provided a protective factor during stressful life events such as the separation of the parental couple: 'sibling affection proved to be protective regardless of the quality of the parent-child relationship' (Gass et al. 2007:172).

By contrast, Deater-Deckard et al. (2002) looked at how sibling relationships were affected by parental difficulties and separation. They studied different family types – married couples, stepfamilies and single parents – and the effect they had on sibling and stepsibling relationships. They did not agree that the sibling relationship always provided a protective factor, and found that the family type had the greatest influence on the quality of the sibling relationship.

These two papers thus note a slightly different impact of parental strife, although what they both address is the unique position of siblings, who share so much history and memory over a consistent period of time in childhood, as Cicirelli (1995) points out.

This joint experience and daily contact not only develops a shared understanding of an individual family's life, but can also be a place of learning about oneself. Howe et al. (2001:453) found that siblings whose relationship allowed what they describe as self-disclosure or 'revealing intimate information about oneself' led to 'socioemotional understanding'. Howe et al. suggest that sibling relationships can influence the way children socialise and understand emotions. However, they note that where this sharing is not possible a sense of mistrust can arise: 'Furthermore, the emotional climate, defined by the degree of warmth and closeness, was associated with children's emotional understanding, in particular their knowledge concerning the reciprocal nature of relationships' (Howe et al. 2001:453). This suggests that if the relationship

between siblings is reasonably good, it helps children develop a greater understanding of relationships in general. These attributes enable understanding of what can occur in the dynamics of the sibling relationship when a sibling becomes unwell.

Edwards et al. (2006:58) wrote: 'These complex interdependences invoke a sense of self, a subjectivity that, as we have seen, is replete with the contradictions of love and hate, pleasure and discomfort, connection and separation.' The sibling bond is formative and influences children as they develop, as does the nature of their parents' relationship. Rustin (2007:28) writes of the importance of the sibling relationship:

We might think of it as a sort of 'we' ego. This is a very important function of siblinghood. The single child who has to share parents with a new arrival in the family does have to deal with rivalry, but at the same time gains a partner.

This 'we-ness' allows some shared history of family life, as well as providing support at times in some families; but this is disrupted when illness of any sort affects one sibling.

2.2.3 Impact of sibling illness

The impact of serious illness on most families is profound. Everyday activities become more difficult and complex, and parents may have to spend large amounts of time apart in hospital with the ill child. This separation of parents and siblings, alongside the stress experienced by all family members, causes inevitable changes in behaviour. Rustin (2007:26) writes of the mother struggling 'to make space for each child', referring to the task of any mother of several children. How much more complex is the task when one child requires so much more attention?

Prchal and Landolt (2012) looked at the experiences of children whose sibling had been diagnosed with cancer. This qualitative study looked at the first half-year following their sibling's diagnosis. They found that children were aware of their sibling's changed appearance and suffering. Children also noted a change in their brother or sister's behaviour, and the fact that they were the centre of attention. The researchers found that siblings had 'intrusive worries' (Prchal and

Landolt 2012:139) on observing their brother or sister's health and changed appearance. This notion of 'intrusive worry' is important, as these worries were connected to feelings of jealousy when the sibling who had cancer received so much attention.

Houtzager et al. (2004) interviewed 56 families with a total of 83 siblings over a period of two years. Their findings offer an explanation of Prchal and Landolt's experience, noting that families adapt over time in the first months following diagnosis. They report a lowering of anxiety, but also link this to 'a balanced family structure that incorporates both stability and change' (Houtzager et al. 2004:600). Families who managed less well were those where the systems were already chaotic. Houtzager et al. note that parental distress was not related to siblings' adjustment difficulties, as these parents were more attuned to distress in their children. However, they also note that parental distress can result in the well siblings hiding their own upset.

Sloper and While (1996) also looked at the adjustment of children whose sibling had been diagnosed with cancer. Once again the sense that families adjusted over time was important, although they also noted that families with pre-existing difficulties should be offered continuing support. Sloper and While (1996:605): reported a comment from a 14-year-old participant: 'What you need to know might hurt you, but you need to know. It will make you feel better if you know it all.' They suggested that those families who were able to talk about the child's illness with family members fared better emotionally, but that overall it was the scale of disruption to family life that was important, as well as the parents' capacity to keep in mind the impact on the well sibling or siblings. The ability to address the concerns felt by siblings, even if those feelings include jealousy and anger, would appear to be vital. Ongoing support beyond the shock of the initial diagnosis would appear to have a helpful impact.

Wilkins and Woodgate (2007) interviewed eight siblings of bone marrow recipients. Of the eight, three were the bone marrow donor. All the participants were girls. Interviews were semi-structured, and the researchers had developed a 'guide to help siblings tell their story' (Wilkins and Woodgate 2007:31). The study did not find any differences emotionally between the donors and non-donors. This was a small qualitative study designed to 'elucidate the richness of

the siblings' experiences' (Wilkins and Woodgate 2007:30). Their participants wanted to be more included in the information regarding the sibling who was unwell: 'They wanted health professionals to be truthful even if it meant discussing negative aspects of their experience' (Wilkins and Woodgate 2007:32).

Prchal and Landolt (2009) review existing reports of psychological interventions with the siblings of children diagnosed with cancer. They report tentatively that such interventions do reduce 'psychological maladjustment' (Prchal and Landolt 2009:1251).

McDonald et al. (2015) evaluated questionnaires given to 106 siblings aged 12–24 years over a period of two and a half years. These tools (the Sibling Cancer Needs Instrument, Family Relationship Index and Sibling Perception Questionnaire) looked at family dynamics, gender, and cultural and linguistic differences. They found that these variables had no discernible impact on distress or unmet needs. They concluded that 'all family types are potentially in need of support' (McDonald et al. 2015:339).

Alderfer et al.'s (2010:802) systematic review, however, notes the finding of 'late onset distress in siblings of cancer patients'. They suggest that this distress can appear up to two years after diagnosis, often at times of transition: 'Whenever distress emerges it should be appropriately addressed' (Alderfer et al. 2010:802).

It would appear that siblings do suffer when a brother or sister is seriously ill. Some families manage better than others, of course, and these tend to be those who include the siblings in any information about the patient. The psychological impact seems to occur both in the early stages of diagnosis and in a resurgence later, sometimes post-treatment. Sharing information in an age-appropriate and timely manner is helpful, and keeping siblings informed is important.

These findings, however, may also be affected by the severity and duration of the illness, and by whether the sibling survives or not. Although cancer in teenagers and young adults accounted for less than 1% of all cancer deaths in the UK in 2012–2014 (www.cancerresearchuk.org/), children can and do die from their disease.

2.2.4 Impact of death on siblings

Emanuel (2014:235) writes of the impact of sibling loss:

Conscious or unconscious phantasies based on sibling rivalry and jealousy – for example, I wish you would throw the new baby in the dustbin or take him back to the hospital – can seem to come true when the sibling becomes ill or dies, even years later.

Emanuel is linking the feelings of hatred felt at times by most siblings (Mitchell 2003:41) to a sense that it is this hatred that has caused the illness or death of the sibling. The sense that the ill or dying child is the favoured one pervades these children's lives. Emanuel (2014:247) quotes the thoughts of a young adult with a severely disabled sibling:

Throughout my desire to die, my brother did his usual life and death dance. Now though, in the place of guilt an anger grew, hardened, and focused on the doctors who kept my brother alive. Their arrogance, their belief in medicine over nature, had made my brother a Frankenstein child. It was time they let him die. Like all those other feelings I kept it inside, I did not speak this thought. I never told anyone I wanted my brother dead. I never have until now.

Blessing (2014) writes of her experiences working with patients who have the death of a sibling in their history. In particular she considers the eating disorders that can develop as a consequence of this loss. She writes of how the sense of a sibling who is 'like me, but not me' (2014:139) enables learning about being part of a family as well as being an individual. The experience of having to share whilst also being jealous means that loving as well as hating feelings can be contained within the relationship. Whilst this is helpful when a sibling is alive, Blessing (2014:153) describes the 'indigestible quality of sibling loss' if that sibling dies, which can result in 'primitive versions of crippling guilt'.

Switzer et al. (1998) looked at the effect of bereavement on adult sibling donors. In summary, they found that these donors felt a sense of self-esteem and what is called 'life satisfaction'. As might be expected, bereaved sibling donors did not feel as if their donation had helped, but they still managed to feel some sense of satisfaction and raised self-esteem from donating, in contrast to

donors whose sibling had survived. The researchers' hypotheses about this unexpected outcome were that the positive feelings of the bereaved siblings may have been due 'in part, to the relief of anxiety and worry that the donors have been experiencing as their sibling struggles to survive the transplant... but... physicians and mental health practitioners should monitor donors' psychological well-being for extended periods' (Switzer et al. 1998:181). These researchers are perhaps indicating that the relief may not be long-lasting. The relief may initially come from a cessation of observing their recipient sibling struggling with the effects of GvHD.

There is no doubt that the loss of a sibling has a profound impact, but donating bone marrow with the intention of aiding that sibling's recovery adds an extra dimension to one's grief. To understand this further, and to look at the emotional impact and quality of this procedure for sibling donors, I now explore what has been written about sibling bone marrow donation.

2.3 Studies of sibling bone marrow donation

2.3.1 Studies of impact on donors

My initial searches in 2011 revealed very few studies involving sibling bone marrow donors. However, there were some surprising finds, such as Henningsen (1980), who reported on the use of psychotherapy to support a young child who had donated bone marrow to her sister. The writer had used psychotherapy to understand her distress and disturbance. Henningsen describes the impact of bone marrow donation on a five-year-old girl called Monika. Henningsen (1980:41) describes how Monika uses drawings to portray her fantasies:

From the way the drawing is structured we can see the inner chaos the child is in. She identifies with the snake who has poison inside.

Unconsciously, the fear of poisoning her sister with her blood [blood donation was seen as an easier way to describe bone marrow donation to such a young child] probably plays a role, in particular as she was frequently furious with her sister.

Henningsen recommends that donors and their parents should receive psychotherapy during the procedure. This is a single case study, and is

interesting as it highlights the fantasies of a small child and her preoccupation with death and poisoning, of herself and her recipient sister. This early work, with a sibling donor who is much younger than those in my study, is important in using a psychoanalytic approach to identify the fantasies of this girl.

Pot-Mees and Zeitlin (1987) looked at the impact of bone marrow transplant on fifteen families where a child aged between two and sixteen had received a bone marrow transplant. Prior to transplant they found the families to be well adjusted; but during transplant, when the family was separated for long periods, parents showed depressive symptoms, and there were behavioural changes noted in all the children. The children who had also been donors showed more distress than those who were not donors. The authors noted that the donors in particular needed to 'digest' the experience, and therefore needed the support of their parents. This proved difficult, as one parent was always at the hospital with the child who was unwell.

Pot-Mees (1989) has also written about the psychosocial effects of bone transplants on children, but focuses more on the recipients than the donor. She concludes that further research is needed for the siblings of such patients, arguing that both sibling donors and non-donors should be investigated for the long-term impact of treatment. Danion-Grilliat (1994:303) also found that in sibling donation there were 'identity problems and identification conflicts on the part of the donor along with the reactivation of previously unconscious sibling rivalry'. Danion-Grilliat noted clinical symptoms in donors that were indicative of 'psychic suffering'. I am especially interested in the finding of 'identity' problems, which may link to the concept of projective identification, which will be discussed later in this chapter in relation to the idea of sharing the same body fluid.

Packman et al. (1997) interviewed 44 siblings aged six to 18 years: 21 donors and 23 non-donors. Only one sibling per family was interviewed. The authors used a semi-structured interview alongside family drawings and self-report measures. They also interviewed the parents, who completed a background questionnaire and a behaviour rating scale. Teacher-rated scales were used to look at the children's behaviour and general demeanour in school. The donors reported significant feelings of anxiety, low self-esteem and stress, which were

greater than those reported by non-donor siblings. Teacher ratings were the opposite, with non-donors showing more problems at school than donor siblings. The researchers found that adolescent donors demonstrated higher levels of post-traumatic stress related to the medical procedure. The quotes from their participants are powerful: 'I felt like I was the one being violated' and 'I felt like I was the target' (Packman et al. 1997:251). However, Packman et al. note that although the donors did appear to struggle, so did the non-donors. This is consistent with the literature on siblings of chronically ill children. They suggest sibling support groups that would enable children to share their feelings.

In contrast, Fortanier et al. (2002) look at anxiety and pain experienced during bone marrow donation, and conclude that no such procedure can be pain- or anxiety-free. Despite the pain, their participants felt that 'the symbolic dimension of gift and familial solidarity... partly compensates for the pain, discomfort and psychological distress' (Fortanier et al. 2002:148). This links not only to Switzer et al. (1998) and Packman et al. (1997), but also to the complexity of the sibling relationship of love and hate.

These interesting outcomes are not supported by Parmar et al. (2003), who write from the perspective of the bone marrow donor. Parmar, now a medical student, reflects on his own experience of donating bone marrow to his brother. This is the only paper I have been able to identify that is written by a sibling donor. He writes of his terror of the procedure, and also of the disruption to his family. He and his co-authors recommend that more attention and support be offered to sibling donors, and that further studies be undertaken to understand the emotional impact on children. Parmar explains that during the transplant the attention was all on his recipient brother, and that at times he felt 'neglected and abandoned' (Parmar et al. 2003:93).

Parmar also mentions that he had throughout his life been allergic to several things, such as nuts and milk. Shortly after the transplant his recipient brother, who had never been allergic to anything, developed the same allergy after eating these foods. Parmar comments how cruel it would have been if his brother had survived the transplant only to die of an allergy acquired through his sibling's donation. Hallstrand et al. (2004) confirm that conditions such as

asthma or allergies can be acquired through bone marrow transplantation. I could not find any papers that addressed the psychological impact of acquired allergy, but Thys et al. (2015:279) write that kidney transplants in adults 'generated a special bond between donor and recipient, characterized by gratitude and admiration, but also raised new expectations concerning the recipient's life style'. Whilst this is a different type of transplant, it implies some continued ownership of the kidney, making it important that the recipient treat it well, as if the two bodies are now intimately connected. A donation of a part of the body is not only a physical act, but clearly connects to the emotions.

In a blog set up on the website of the Anthony Nolan Trust, which registers unrelated bone marrow donors, adult recipient Nicky (2016) writes honestly about her bone marrow transplant. She is clear that she is very grateful for the life-saving marrow, but she explains that she has found receiving blood and bone marrow very challenging: 'I really struggled with the idea of a blood transfusion, someone else's blood. It made me feel somehow as if I'd be less myself if I had it – because *I am me.*'

The donation of a body part, whether it is blood or an organ, evokes powerful feelings. Wiener et al.'s (2007:8) review of the sibling donor experience with donors between the ages of nine and 28 concludes that 'psychological distress exists before, during, and after stem cell donation and transplantation, regardless of outcome'. This detailed review raises some concerns about the sense of having 'no choice' (Wiener et al. 2007:6). The authors acknowledge the complexity of researching the responses of family and individuals to this medical procedure, but feel more studies are urgently needed. Wiener et al. (2008) follow up the 2007 review, describing their research with 16 sibling donors between the ages of seven and 18, exploring their experiences pre-donation, at stem cell harvest and post-donation. They found that the older donors were more anxious than younger donors, which they felt indicated those donors' greater comprehension of the procedure and its importance. They suggested that 'it is important to assess for feelings of guilt if the recipient sibling develops complications such as graft failure, GVHD, or disease relapse' (Wiener et al. 2008:306). It is as if the donor has *caused* some horrible condition or reaction, despite the initial reason for donation being to offer salvation to an ill sibling. Wiener et al. are aware that the donor sees the

recipient's post-transplant state as a clear indicator of the donation's 'goodness' or success. They conclude that more research is needed with 'age-appropriate interventions for this often overlooked population' (Wiener et al. 2008:307).

I found only one paper about multiple bone marrow donations. The patients involved had thalassemia, a non-cancerous disease of the blood. Biral et al. (2008) look at safety, efficacy and ethical issues. This is largely a medical paper, but the researchers speak of the donors' 'compelled altruism' (Biral et al. 2008:381) and the need for medical teams to be aware of this, especially when further donations are required. They carefully explore alternatives, but conclude that all seven of the paediatric patients did experience engraftment on second donation. This success may make alternatives difficult to contemplate.

Siblings may have a more developed sense of responsibility and connection to each other. Thus the idea of 'no choice' (Wiener et al. 2008) becomes linked to 'compelled altruism' (Biral et al. 2008). It may be difficult for a child to donate once and then refuse further donations. Picoult (2004) wrote a fictional account of just such a dilemma. The donor, in this case a so-called rescue baby born to provide vital matched bone marrow, refuses at 13 to donate a kidney to her still-struggling sister: 'I didn't come to see Kate because it would make me feel better. I came because without her, it's hard to remember who I am' (Picoult 2004:136). Whilst Picoult's account is fiction, her description of this donor's response is supported by research: 'I felt like I was the one being violated' (Packman et al. 1997:251). Kazuo Ishiguro's *Never Let Me Go* (2005) also seems to address the fantasy of being a donor or recipient. His fictional novel depicts a world where everyone has an exact clone, a living bank of potential organs. This may be linked to the idea of 'rescue babies', but I think touches on what some of the sibling donors feel when they donate their bone marrow – even more so if they are required to donate more than once.

Pentz et al. (2014) conducted qualitative interviews with 119 families pre-transplant, and then a further two times post-transplant. They concluded that 'most family members did not view sibling typing and donation as a choice' (Pentz et al. 2014:8). They report that families did not see this as a concern and generally were positive about the procedure. However, Pentz et al. (2014:4) do also write of the 'notable concerns' of two of the donors. One 12-year-old felt he

had not been sufficiently informed about the process, and found the G-CSF injections especially painful. Pentz et al. (2014:9) suggest follow-up for the sibling donor 'to assess and ameliorate concerns'. My sense is that it would be difficult for families to view typing or donation any differently, since a 100% sibling match is the best match possible for the transplant procedure.

D'Auria et al. (2015) also sought to understand what it felt like to be a sibling donor between the ages of 10 and 30. They recruited eight participants and interviewed them once, with open-ended questions. These interviews were then analysed using grounded theory. Once again there was a sense of 'no choice' and that of course they would 'step up'; otherwise there was in their minds a risk of their sibling dying. The participants described a sense of 'saving my sister's (or brother's) life' (D'Auria 2015:449) as their main memory. One commented on the guilt that they would have felt if they had refused. The donors were fearful about the outcome, and one in particular said: 'I just said "I hope I'm not the one that do my brother in. I just hope it ain't me." I mean... it would have been something man if it was me, it [would have] killed me' (D'Auria 2015:450). The responsibility felt by these young sibling donors is powerful. D'Auria et al. call for more research, in particular to look at the sibling bond between donors and recipients, which may 'change beyond the adolescent and young adult periods' (D'Auria et al. 2015:453).

Weaver et al. (2015) write of the 'sibling shadow', whereby sibling donors (and also non-sibling donors) seem to be rather hidden from the view of psychological services. This paper highlights some of the effects of donation, including the G-CSF injections and the anxiety siblings, particularly in the adolescent group, feel when they face the medical procedures for extracting bone marrow. The authors comment on the very particular challenge of adolescence, 'a time of vulnerable biological and social-role life changes' (Weaver et al. 2015:1). They suggest that as transplants provide an increasing chance of survival for diseases such as high-risk leukaemia, more siblings are becoming donors. They conclude that research attention has been focused on the sibling who is sick; the donor sibling's needs are obscured from sight as if in the shadow of their recipient sibling. They argue that further studies may 'shed light... on this generally overlooked but remarkably generous, brave, and invaluable population' (Weaver et al. 2015:3–4).

McDonald et al. (2015:339) also suggest that this sibling group is 'understudied', and comment that family structure and ethnicity have no bearing on the potential need for emotional support. However, the ages of the sibling and sibling donor do make a difference, they suggest, exposing adolescent siblings to greater stress due to their increased capacity to understand the seriousness of their sibling's illness.

Weaver et al. (2015) and McDonald et al. (2015) both make particular reference to the adolescent years as making this procedure more challenging. In the next section I look at literature that focuses on this period in the human life span.

2.3.2 Impact of adolescence

Margot Waddell (1998:141) writes that adolescence 'is now regarded as highly important in a person's development, a crucial period of time during which essential aspects of the personality become shaped'. She writes of the immense upheaval of this period, with a return to impulses and desires experienced in infancy. The difference for the adolescent is that now they are capable of acting on such urges: 'The child is faced with an alarming situation; he can actually enact his genital desires and destructive feelings' (Waddell 1998:143). There is a sense in which fantasy in sexual matters, physical strength and differing emotional states can become an important aspect when considering the donation of bone marrow.

The relationships with siblings will inevitably change and develop, as Bank and Kahn (1982:64) write: 'With the start of adolescence, the sibling relationship is much more likely to change. Adolescence is a quintessential period for change to occur as a result of both physiological development and shifting social opportunities.' They go on to write about the sense of loss siblings may experience as one of them begins to change, developing new friends and modes of dress – in other words, becoming different.

The literature discussed above notes the impact on siblings when one becomes ill and their suffering is apparent. As well as bringing huge changes physically and emotionally, adolescence also brings greater awareness and understanding: 'Additionally, AYA [Adolescent and Young Adults] siblings often have a greater understanding of the seriousness of cancer' (McDonald et al. 2015:333).

This joint challenge of individual and personal change and an awareness of the change in the unwell sibling provides a further challenge if a young person then receives a request to donate bone marrow during 'this time of turbulence, disturbance and struggle, often of inner uncertainties and chaos, the adolescent's growing discovery of his own sexually maturing body and physical strength' (Wise (2000:1). The awareness of the developing body, both in the donor and in the recipient, may provide a link between the theory of projective identification and the ordinary interest in sex and sexual identity present in all adolescents. I will address the psychoanalytic theory of projective identification later in this chapter. First I will look at psychoanalytic views on sexuality, as the donation of what is essentially a body fluid to a sibling may in fantasy become linked to fears of a sexual act.

Alice Polomeni (2017) spoke of 'unconscious fantasies of incest or twinning' in her presentation to the European Bone Marrow Transplant conference in March 2017. She was referring to the adult patients she sees in her role as a clinical psychologist in Paris, but her words link with Nicky (2016), the recipient quoted earlier, who described her sense of the 'other' inside her.

Flynn (2000:69) writes that the psychoanalytic understanding of adolescence has only developed in the last 50 years, and that prior to this it was seen as important because it was the time of growing sexual maturity. Freud believed that an awareness of sexuality is present from birth and does not suddenly emerge in adolescence: 'There seems no doubt that the germs of sexual impulses are already present in the new-born child' (Freud 1991:92). Freud wrote that these impulses are repressed but continue to develop over time, and re-emerge in a more observable form at the age of three or four years. However, whilst at this age the interest in body parts seems straightforward, in adolescence they take on new meaning.

This view does not take into account the other challenges of adolescence, when 'there is normally a loosening of the connection with the family, both from the incestuous object and phantasies towards the mother or father, and from parental authority' (Flynn 2000:70). Mitchell (2003) might also add the incestuous fantasy connected to a sibling. These feelings are deeply disturbing to the adolescent. Flynn (2000:72) notes that not only in relation to sexual

impulses but also more generally, 'the adolescent both experiences more negative feelings and hides them more, and readily splits people and things into good and bad.'

Klein (1989) wrote of the need for the adolescent to keep anxiety at bay, suggesting that they manage this more successfully through activities. This need for action in adolescence is well recognised, as it will often show itself in the form of 'defiance and rebelliousness' (Klein 1989:80), but it presents a greater challenge when one sibling is unwell. Klein developed these ideas further, and her paper 'Notes on some schizoid mechanisms' (Klein 1988a) discussed how an infant would use primitive splitting mechanisms to manage feelings of both love and hate directed towards the breast/mother, which feeds but at times frustrates the infant when the latter's needs are not attended to or when discomfort abounds in whatever form. As Segal (1973:25) explains:

As with the death instinct, so with the libido. The ego projects part of it outwards, and the remainder is used to establish a libidinal relationship to this ideal object... the primary object, the breast, being at this stage split into two parts, the ideal breast and the persecutory one.

It is from this early infantile projection of the death instinct that another important mechanism develops: that of projective identification. It is this mechanism that I will now discuss in relation to adolescence.

2.3.3 Projective identification, consent and refusal

Projective identification is the basis of many anxiety-situations, of which I shall mention a few. The phantasy of forcefully entering the object gives rise to anxieties relating to the dangers threatening the subject from within the object. For instance, the impulses to control an object from within it stir up the fear of being controlled and persecuted by it. By introjecting and re-introjecting the forcefully entered object, the subject's feelings of inner persecution are strongly reinforced; all the more since the re-introjected object is felt to contain the dangerous aspects of the self (Segal 1973:11).

This psychoanalytic theory may help to explain the fears that sibling donors have when a recipient sibling develops GvHD, or when they experience a terror that their donation may kill the recipient, as noted by a donor above.

The experience of seeing a recipient sibling develop some of the more visible signs of GvHD may feel like a concrete manifestation of projective identification. Ogden (1982:1) elucidates further on this complex theory:

Projective identification is a concept that addresses the way in which feeling states corresponding to unconscious fantasies of one person (the projector) are engendered in and processed by another person (the recipient), that is, the way in which one person makes another person experience and contain an aspect of himself.

Flynn (2000) describes how the ordinary adolescent may have a shifting state of mind throughout a day, and that to work with them one must be prepared for positive as well as negative projections. This may also be an important link to the sibling donor, who may have already endured months of family disruption connected to their ill sibling: as the literature discussed above highlights, these siblings will feel a mixture of concern and envy. It is this important shifting state that is so relevant in the period of adolescence.

Edwards et al. (2006:42) use the theory of projective identification to further their understanding of this shifting relationship between siblings:

Here, the denied part of the self is projected, not so much onto as *into* another person. Projection and projective identification can occur not only because one has to get rid of the intolerably bad bits of oneself. It is important to remember that these denied parts can be *good* as well as bad. It can be equally difficult for a person to own their positive qualities.

Bank and Kahn (1982:256) also note the way one may recognise a part of oneself in a sibling, a part that one dislikes or feels guilty about: 'The well sibling who sees his or her old forbidden self – writ large in the brother or sister, unconsciously disowns that part of himself.' This connection between siblings becomes more complex because of the medical procedure of transplant using a sibling's bone marrow. Alby (1990:78) writes of the impact on the recipient

sibling, who, whilst recognising the bone marrow as a chance for life, can also feel fearful of 'being taken over by the donor'.

The donation, whilst often life saving, cannot always be viewed merely as a helpful medical procedure. Alby (1990:78) mentions the psychological repercussions of GvHD but does not expand on this, although she does also say that 'refusals to donate are very rare and usually indicate some deeper "dramatic conflict".' Alby implies that a refusal to donate is rare because it might feel as if difficult or conflicted feelings for the sibling would be exposed; when refusal does occur, it implies that there is a deep rift between the siblings.

Daune (2014:103), writing more from the recipient viewpoint, notes that 'a medical condition will rearrange the sense of identity among these siblings, where "I" had become "we".' There seems to be an almost concrete sense of projective identification. The recipient and donor become 'we', no longer an individual. Daune (2014:108) considers the feelings within the family about who is a full match and who is not, and who has inherited the 'bad genes' from the parents: 'Certainly, there is a potential sharing of status, but does the question of who is incorporating whom apply? As I have already shown, the donation gives rise to anxieties and fantasies.' Again, there is a sense that individual identities can be lost due to a sharing (through donation) of bone marrow.

The theory of projective identification, as written about by Klein (1988a) and developed by other clinicians such as Segal (1973) and Ogden (1982), demonstrates how painful or uncomfortable feelings can be got rid of into others. It is an important capacity which comes into being in the early days after birth and allows the infant to alert the mother to its state. This capacity develops and includes the projection of good parts of the self as well as bad. The writers discussed above note that in adolescence this capacity is more active, due to the shifting states of mind of that age group. In the case of adolescent sibling bone marrow donation which is undertaken because of severe illness, the sibling may witness the effects of that donation – as the body fights and hopefully accepts the donated bone marrow or stem cells – as a concrete example of their mixed feelings towards their ill sibling. The death of the ill sibling may also be felt to be due to those more conflicted feelings. Whilst some of the writers above are writing of their experience with adult donors and

recipients, there is also evidence of the greater challenge for the adolescent, who because of their stage of life is already in a state of flux and shifting identifications.

The literature supports the idea that having a sibling with a chronic illness or cancer puts a great strain on the emotional well-being of siblings. To refuse to donate has been shown to be almost impossible because of the sense of 'no choice' as well as the impact of seeing the effects of GvHD. It would seem that the theory of projective identification is helpful for understanding the complex feelings of adolescents, who may feel that they have caused these side effects by their mixed feelings for the ill sibling, and at worst may even feel that they have caused their illness and death.

However, for a sibling to refuse to be tested or to donate would also be difficult, for the reasons discussed above. Biral et al. (2008:381) wrote of their sense of 'compelled altruism' in donors who needed to donate more than once to a sibling. It is this phrase and the nature of altruism, which captures something of the dilemma of the sibling donor, that I now explore further.

2.3.4 Altruism

The phrase 'compelled altruism' was used by Biral et al. (2008) in a paper looking at safety, efficacy and ethical issues when a sibling donor is required for more than one donation. However, the paper does seem to acknowledge ambivalence among medical teams about using a sibling donor more than once, with its use of the word 'compelled' indicating the sense of 'no choice' (cf. Weiner et al. 2008; Pentz et al. 2014; D'Auria et al. 2015).

Altruism generally refers to a selfless act which does not benefit the giver, only the recipient. Tankersley et al. (2007) note that the neural mechanisms that cause someone to be altruistic are not understood, but those who are empathetic are more likely to be altruistic.

Mikulincer et al. (2005) describe five experiments undertaken in the US and Israel to test the hypothesis that a secure attachment encourages greater compassion and altruistic behaviours. The participants were a group of people with mixed attachment ratings, and results were consistent across the two countries. The experiment required the participants to view a young woman

having to complete certain tasks which she found distressing, for example petting a large spider. Those participants who had been found to have secure attachments all responded with empathy and offered to take the young woman's place. Mikulincer et al. (2005:838) conclude: 'we have shown that attachment security, whether dispositionally present or contextually enhanced, fosters compassion and altruism and appears to work similarly in different societies.'

Music (2014:43) similarly draws on attachment theory to theorise altruism: 'Altruistic tendencies and empathy normally emerge alongside being able to conceptualise oneself as part of a story with a past, present and a future.' He explains that selfish tendencies must be inhibited, whilst empathy must be developed. In time he believes that compassion develops for the suffering of others, but that these attributes only develop where attachments have been secure.

Burnsall (2003) investigated the emotional impact on children whose brother or sister had an acquired brain injury following an accident. Burnsall looked at the strategies used by these siblings to regain their 'equilibrium'. She found that siblings were 'sacrificing' aspects of their lives in order to regain their own and their family's equilibrium; also, since the injury had come about through an accident, there was a realisation of the vulnerability of life – 'it could have been me.' There was also a sense of self-blame, a feeling that they could have prevented the accident. This may also be linked to the idea of projective identification and a fear that there may have been a wish that the sibling would be hurt. However, Burnsall (2003) also looks at altruism, and finds the sibling's actions are similar to the behaviours of their parents. She notes numerous incidents of siblings including their brother or sister in activities that they would not normally consider, as well as other incidents when siblings set aside their needs for the injured sibling.

Hamilton (1964) wrote of altruism that it causes an individual to value a sibling half as much as themselves. He stated that this was because all siblings share at least half of their genes. This seems mechanical, but also oddly linked to sibling bone marrow donation, which must be a 100% match. However, it does

not allow for the discovery in the literature review that siblings are bound together through love as well as hate and a sense of family duty.

Gintis et al. (2003:169) wrote of the challenge of understanding altruistic acts, and concluded that more study is required: 'we believe that more attention should be paid to... the origin and nature of social emotions (including guilt, shame, empathy, ethnic identity, and ethnic hatred).' Although Gintis et al. (2003) were connecting this to the wider social emotions, not just familial emotions, I believe all of those feelings apply in this research and make the understanding of altruistic acts especially difficult and complex.

I am reminded of the Memorial to Heroic Self Sacrifice in London's Postman's Park, where deeds of great courage are recorded, among them touching details of three boys aged eight, nine and 10 and a girl of 19 who lost their lives attempting to save the life of a younger sibling. The literature seems to point to the importance of a sense of 'no choice' for these donor siblings, who feel that refusal could result in the death of the sibling. This inescapable element of a sibling bond also produces anxiety, and can often result in what seem to be considered acts of great altruism on the part of sibling donors. There is an important question here: if the altruistic act is compelled or comes about through a sense of 'no choice', does it remain an act of true altruism? Accounts of acts of heroism, as with the children remembered in Postman's Park, are very powerful, but perhaps those young people acted for many different reasons: love, duty, guilt, shame or empathy, feelings that for many are too powerful to resist, despite the risk to the self. I will explore this in more depth in Chapter Five.

In the next chapter I will discuss research methods and the methodology I decided to use to understand and interpret my transcripts.

CHAPTER THREE: METHODOLOGY

3.1 Aims of the study

My aim is to explore the emotional impact of the whole process of donation on sibling bone marrow donors. The focus of the study is to explore this for sibling donors between the ages of 13 and 18, and to think about whether the characteristics of being both a sibling and an adolescent add any particular emotional complexity to the impact of this medical procedure. I explore the roots of any emotional impact that bone marrow donation has, and make initial recommendations as to whether psychological support would be helpful and what form it should take.

3.2 Rationale for the study

A number of research studies have already examined the experiences of sibling bone marrow donors, the physical impact of donation, and some of the emotions experienced by the donors. I discussed these works in my review of the literature in Chapter Two. What became clear from these studies was a sense of 'no choice' on the part of the sibling donor, since the recipient was a brother or sister; and that whilst in part there was a genuine willingness to help, there were also feelings of anxiety linked to side effects for the recipient and a sense of responsibility for the outcome. Whilst some of these studies looked at the emotional impact on adolescent donors, none addressed the deeper fears and fantasies that seemed to be linked to donating a part of the body to a sibling during a period of physical and emotional development, as for example in the case of the young woman I spoke of in the Introduction.

This young woman, who was 18 when I met her in the consultant's clinic, made a throwaway comment before her second donation that she felt she had shrunk. That comment could easily be dismissed – not in an unkind way, but by giving her clear practical evidence that she had not shrunk. It may have been, however, that she needed to have it acknowledged that she felt diminished by the demand for more of her marrow. I interviewed this person not as a research participant, but in my capacity as a child and adolescent psychotherapist.

However, it raised the question of whether donors generally might feel that they are physically diminished by donation, or whether this anxiety had a particular resonance for her. It would have been hard for her to refuse to donate, and indeed she may not have even considered refusing, but she seemed to be asking for some thoughtful attention. This young woman's experience is just one example of several that came to my attention and that of the haematology consultant over a period of a year after we started to work together. During this time I saw about five donors between the ages of 13 and 18. One of these was anxious that she would lose her fertility and her mobility if she donated, and another that she alone would be responsible if her brother died. These examples emphasise that bone marrow donation in adolescence, at least for some donors, appears to raise many feelings, fears and importantly fantasies, which I explore further in this research.

Most bone marrow or living organ donations come from unrelated donors. Despite this lack of familial connection, donors and recipients often wish for some contact, either to thank the donor or to enquire about the health of the recipient. The Anthony Nolan Trust is one of the largest bone marrow registers, and it provides an illuminating and honest blog written by a recipient, Nicky (2016). In it she writes of her feelings, both about her donor's cells and also about having a blood transfusion:

At which point... I lost it, in all honesty, it may sound silly, but I really struggled with the idea of a blood transfusion, someone else's blood in me. It made me feel somehow as if I'd be less myself if I had it – because *I am me*.

Later she admits: 'I still haven't got over the thought of having someone else's stem cells... But there was a deeper feeling, beyond squeamishness; I was worried that I wasn't me anymore.' Nicky is a 50-year-old woman, and she is describing her feeling that, despite its life-saving quality, the donated bone marrow remains another's body fluid. Her feelings are powerful, as though she has been invaded. Whilst this is a recipient's response to a transplant, it demonstrates a powerful feeling aroused by the donation of unrelated bone marrow. It seems reasonable to suppose that donors who are related, and in particular donors in their adolescent years when relationships are in a state of

flux, may have some unconscious as well as conscious feelings about this altruistic act for a sibling with whom they probably have a complex relationship. Therefore it can be argued that there is an ethical responsibility, if doctors are asking and enabling sibling donors to donate, to find out more about the impact of what they are asking.

3.3 The historical development of research methods

Rustin (2001) writes of the polarity between science and non-science, and he traces the route by which research in the field of psychoanalysis has developed. He describes historical changes in research methods and their acceptability, and I now summarise these developments to show my journey in selecting a research methodology.

In the positivist methods of scientific philosophy prior to Thomas Kuhn, a research approach was required that started with the establishment of a hypothesis and an approach to test and falsify it. Kuhn (1962) explored a new philosophical approach to what counts as scientific research. Instead of a rigid formulation, he proposed that scientific discoveries involved many evolutions. During these changes in thinking, new 'paradigms' would be developed, extending our way of approaching research and thinking about the social world: this was his 'revolutionary science'.

Bruno Latour (1987) extended this 'paradigm shift' by describing how discoveries made in the laboratory become recognised and used outside it. He cited the case of Pasteur and his discoveries in the study of bacteria. These were made in the controlled environment of the scientific laboratory, but the findings were able to be transferred to working dairy farms, where pasteurisation was introduced to reduce the spread of disease to humans through the consumption of untreated milk. Rustin (2001) makes the connection between the scientific laboratory and the psychoanalyst's consulting room, and argues that what we learn in the consulting room about individual human nature is important for our understanding of human emotion and distress. Sigmund Freud (1991:71) insisted that psychoanalysis was a special case within science because of 'the inseparable bond between cure and research': that his patients recovered from their malaise was proof enough that psychoanalysis worked.

Freud believed that from this individual work in the consulting room it was possible to begin to generate understanding about human emotions.

This challenged positivism, which only saw scientific methods as valid if demonstrated through the repeated testing and falsification of hypotheses. Positivism is helpful in the physical sciences, where variables can be controlled. It has been valuable to ensure the safe development of drugs and medications used to treat patients. The National Institute for Clinical Excellence ensures that drug trials are safely run, and that only with proof of a drug's validity will it be used. The bone marrow transplant team have seen and been part of the development of new and more refined drugs that over the course of some years have led to huge improvements in the transplant journey. This is only possible with repeated testing and clear clinical evidence gained through positivist methods.

Positivism therefore has a vital role in this area of research. However, in the area of social research a more intimate understanding of the participant is needed. Constructivism or interpretivism holds that the world is 'not straightforwardly perceivable because it is *constructed* by each of us in a different way' (Thomas 2009:75). Freud did at times show his despair that the 'science of psychoanalysis' was rather different from a positivist view of science. Desmarias (2007) notes Freud's envy of the physicists and mathematicians who could find and demonstrate concrete evidence for their theories with numbers and charts, whilst psychoanalysis may at times feel like mythology.

Paradigms are ways to think about and study phenomena (not just social life) and the choices we make about what we want to learn from our research. The paradigm and the research method therefore should fit what needs to be understood. Given that I am seeking to explore at a deep level the subjective experience of individual sibling donors, I have opted for a social-constructivist (rather than positivist) paradigm. Within such a broad approach I have adopted a qualitative interpretivist approach that will allow the systematic, rigorous exploration of the sibling donor experience. In particular, I use my clinical training as a child and adolescent psychotherapist to access the subtle and nuanced feelings that may be aroused, as illustrated above in relation to the young woman and her fear of being physically diminished. Thomas (2009:78)

describes how the researcher using an interpretivist method will 'understand the particular, contributing to building a framework of multiple realities'. The aim of the researcher is to be able to interact with participants, to hear their 'perceptions, feelings, ideas, thoughts' (Thomas 2009:78).

3.4 Qualitative research design using case studies

Barker et al. (2002:72) write about the foundations of qualitative research:

- Qualitative research uses language as its raw material.
- It aims to study people's thoughts, experiences, feelings, or use of language in depth and detail.
- The main advantage of qualitative methods is that they enable thick description.

As a new researcher with a small number of participants, I wanted to use my training in psychoanalytic psychotherapy as one way of understanding the detail and processes of the sibling donors' thoughts and feelings. I looked for a research method that might allow this. I wanted to use a qualitative rather than a quantitative method in order to obtain this detail and nuance regarding the individual experiences of the sibling donors, as expressed in their narrated accounts using their own language. I work full-time in a busy teenage and young adult oncology department, so I therefore chose to interview sibling donors from that site only. There are approximately 20 bone marrow transplants a year in this unit, and of these up to eight may involve bone marrow donated by a sibling. I was therefore aware that the number of available participants would be limited.

Hollway (2004) and Hollway and Jefferson (2000) have used psychoanalytic techniques in interpretivist research as one way of gathering data sensitive to both external circumstance and internal emotion. Hollway (2004:29) points to the limitations of conventional methods of qualitative enquiry, where 'the idea of a socially constructed individual... is intolerant of the idea of internal mental states, conscious and unconscious, that are partially independent of language.' Hollway is writing here of the 'defended subject': whilst many participants may not always say what they feel, Hollway is noting the complexity and meaning of conscious and unconscious defences. It may be important to note what such participants do not say, which links to Barker et al.'s (2002) idea of language as

'raw material' to be looked at and studied in detail. To achieve this degree of depth, it is necessary to limit the number of participants. Midgley (2004) points out that although qualitative methods offer rich detail, they lead by their very nature to smaller studies, sometimes involving only a few participants – as with mine. This can leave such studies open to criticism. Vickers (1965) makes a similar argument, saying that whilst generalisation is not possible in case studies, 'thick description' is, and from this we gain a rich picture of the subject. Midgley (2004:106) finds that in recent years criticism of the value of case studies has changed:

Quantitative studies can only show a statistical correlation between two variables (when X happens Y usually happens too), while *qualitative* approaches can actually help us to understand the causal links by going beyond sheer association to identify causal mechanisms (Y tends to follow X because...).

3.4.1 Multiple and single case studies

Weaver et al. (2015:1) present a powerful reason for more in-depth studies such as case studies:

A shadow represents a dark image or a faint semblance, such as a trailing presence. In order to prevent sibling donors of hematopoietic cells from feeling that their generous role is cast in shadow, care teams have a meaningful opportunity to bring the experience of sibling donors into the light.

These researchers are describing how sibling donors may have felt – and indeed even been – hidden from view because of the greater interest in the complex medical procedure for recipients. Weaver et al. (2015) encourage further study of and attention to this somewhat hidden group.

In this research design, therefore, in order to look in a more detailed way at this group, I decided to use a number of case studies. Rustin (2001:104–105) addresses the justification for researching single case studies:

Case examples have always been important sources of discovery in sociology... It is because it is through single cases that self-reflection,

decision and action in human lives can best be explored and represented that the single case study is essential to human understanding.

Rustin refers to the 'luminosity' provided through the single case. Other researchers have also referred to the particular power of the case study to 'illuminate': 'the essence of a case study, the central tendency among all types of case study, is that it tries to illuminate a decision or set of decisions: why they were taken, how they were implemented, and with what result' (Schramm 1971:6). Thomas (2009:115) also uses the analogy of a research study shining a light on or illuminating a particular subject. He states that an interpretive study can also be illuminative: 'The aim is gain rich, detailed understanding of the case by examining aspects of its detail.' Thus the small case study would seem to suit the topic of investigating the intimate feelings and emotions felt by sibling bone marrow donors, because it aims to capture the unique qualities of the individual.

Thomas (2009) explains that if one chooses to research a small number of cases, one cannot then generalise one's findings to the broader population. Therefore he advises that the participants in such intimate research should be carefully selected on the basis of age and gender, to get as wide a range of participants as possible. I have learnt from my medical colleagues that adolescent sibling bone marrow donors are relatively few in number; this is due to the fact that adolescents diagnosed with cancer are few in comparison with the adult population. As stated before, a sibling has a one in four chance of being a match, so from the outset the number of participants in the study was likely to be small. The study was therefore designed as a small number of discrete single case studies.

Whilst the case study enables 'rich, detailed understanding' (Thomas 2009:115), the understanding can only be of the specific group of participants, and any application of the findings beyond that needs to be made with great caution. James Patrick (1973), a sociologist, wrote a study of a Glasgow gang by actually joining the gang and learning about it from the inside. Geertz (1975:42) criticises the notion of the 'inside' researcher, arguing that for the anthropologist, understanding comes not from 'extraordinary empathy but readily observable symbolic forms... to grasp the unarticulated concepts that

inform the lives and cultures of other peoples'. Whilst Patrick (1973) could only describe and write about his understanding of one gang, as each gang has its own character, he could hypothesise as to the possible nature of the other gangs he met during that study.

Barker et al. (2002:162) describe small studies using cases as a way of 'combining research and practice' which allows clinicians to undertake research within their working practice. They also describe clinicians using a narrative approach, like Freud, or more 'structured studies using systemic measurement of process and outcome' (Barker et al. 2002:162). Like Thomas, they note that small studies allow for 'individual uniqueness and complexity' (Barker et al. 2002:162), but not generalisation.

Willig (2013:103) makes the distinction between *descriptive* case studies and *explanatory* case studies. The first is concerned with 'providing a detailed description of the phenomenon within its context', whilst explanatory case studies 'aim to generate explanations for the occurrences with which they are concerned'. This provides a helpful distinction, and allows the researcher to find a way of investigating particular phenomena or particular and restricted groups such as adolescent sibling bone marrow donors. Willig also describes how because case studies often involve complex human interactions, they can result in the generation of new theories, as with Freud's descriptions of his psychoanalytic work.

3.5 Reflexivity and attention to subjectivity.

The use of reflexivity allows attention to the subjectivity of the researcher so that this can be consciously used within the research. Willig (2013) makes the distinction between epistemological reflexivity and personal reflexivity. Personal reflexivity involves reflecting upon the ways in which our own values, experiences, interests, beliefs, political commitments, wider aims in life and social identities have shaped the research. Epistemological reflexivity connects to the questions we have asked our participants, and to 'how... the design of the study and the method of analysis [have] "constructed" the data and the findings' (Willig 2013:10). Willig suggests that epistemological reflexivity enables researchers to think about assumptions that can be made about the research and the findings that result from it.

Doane (2003:93) believes that personal reflexivity allows 'a way of accessing knowledge of any *human experience*' (2003:93). Doane also notes that it is important for the researcher to 'let go of preoccupations with the self and to be in a place of complete attention' (Doane 2003:99).

My immersion in the team and the work of a teenage cancer unit whilst undertaking the research needs further discussion. Fontana and Frey (1998:57) point to the importance of 'the establishment of a human-to-human relation with the respondent and the desire to understand rather than to explain'. This seemed especially fitting for someone with a psychotherapy training like mine. Hollway and Jefferson (2000:65) discuss the use of reflexivity and how this can 'serve both to guard against bad interpretations and to assist with good ones'. In sociology reflexivity is regarded as a way of being able to 'self-reference' – in other words, to be aware of the feelings raised in oneself. This too is perhaps especially fitting for someone with a background in psychoanalytic psychotherapy.

This made me examine my own motivation for undertaking this study and whether, given my role in my clinical work as someone who offers emotional support to patients experiencing difficulties, my approach as a researcher may have reflected a problem orientated approach, an expectation of difficulties. However, I have worked in my supervision and professional development to evolve my clinical practice at the hospital to be more attentive to the positive aspects of patients' lives. I feel I was able to use this professional development in my research role (in both the interviews and their analysis) to also be alert to the positive aspects of donors' experiences as well as the more difficult.

Brown (2006:193) writes of the importance of reflexivity in research, but also of its limitations:

However, with important reminders of the limits of reflexivity in the social research process in mind, we can still use psychoanalytic concepts and methods in order to understand our subjects further (in a conceptual and empirical way) and in order to look at the research process and our place within it.

Hollway and Jefferson (2000:19) use the term 'defended subject' and draw upon Melanie Klein's theory about unconscious defences, which she proposed

we all utilise to protect ourselves from anxiety. In the context of research methodology, it both highlights the researcher's own defences, as Gadd (2004) notes below, and also alerts the researcher to the possible defences of the participants.

Gadd (2004) gives a particularly honest account of his research with men who have been violent to their partners. As a male researcher, he found himself wanting to distance himself from any sense of identification with the men he was interviewing: 'I prioritised my desire to get the facts over and above a respect for [the participant's] vulnerable feelings' (Gadd 2004:394). Gadd is reflexive about his feelings of horror at the participants' violence towards women, realising that he did not want to hear about his participants' vulnerability in case he felt some sympathy for them. He felt that he needed to distance himself from their acts of violence by seeing them only as violent men; but as he states above, through his capacity to be reflexive he became aware of his wish to rush through the interviews.

Ellingson (1998:54) writes a powerful account of her research in a large oncology unit. She describes how this inadvertently led to her reflecting on her own experiences as a cancer patient: 'Rather than seeking to eliminate the "messiness" of real experience by defining and quantifying it, I embraced the mess as a source of meaning and constructed a dynamic, empathetic perspective on the clinic.'

It may have been that my anxiety as a researcher led me to avoid a deeper exploration of feelings in the participant. I witness at first hand the pain and desperation of parents when their child was dangerously ill. It may be that this prevented me from being more inquisitive about my participants, for fear of generating further family pain should reluctance or ambivalence on the part of the donor be revealed. Balbernie (2003) highlights the importance of gathering rich data for a research project without exploiting the research participant and leaving them vulnerable. I am very much aware of Balbernie's argument that boundaries are a vital part of both the therapeutic and the researcher role. I shall address this further in the section on ethics and ethical considerations, and in the discussion in relation to the difference between being the therapist and being the researcher.

The methodology of my study, which was on a small scale, was intended to enable more detail to be explored, and to generate more capacity to look at the meaning of comments such as those of the young woman mentioned at the start of this chapter. As a child and adolescent psychotherapist, I had a particular set of interviewing skills – underpinned by theoretical conceptions – to undertake the investigation and attempt to gain more understanding of what it meant to offer up a part of yourself to a sibling.

I turn now to discuss the clinical context for the fieldwork.

3.6 Clinical context and research site

Baxter and Jack (2008:545) wrote a case study of decision-making among nursing students: 'the case could not be considered without the context, the School of Nursing, and more specifically the clinical and classroom setting.' My research site was also my place of work, and it allowed me to witness the struggles of the families facing a bone marrow transplant. I had worked at this large hospital since 2003, predominantly in the paediatric and adolescent cancer division. I worked closely with the haematology team in particular. When I began this work there were only six adolescent beds available for this group. I met all the families, and whilst I may not have offered specific psychotherapeutic support, I was a familiar face on the unit. When we moved to the current hospital site the number of haematology beds increased, as did the teenage cancer unit. Bone marrow transplants increased and I became the HTA AA, interviewing sibling donors under the age of 18. The creation of this new role was an attempt to guard against coercion or bribery being used to persuade siblings to be tested or matched siblings to donate. It was an important step, and the role has continued to evolve and develop, offering greater attention to the role of sibling donors.

This official role gave me a more detailed view of what the patient and family had to endure on the journey to transplant. I witnessed the distress of family and sibling when the sibling's fear of needles was too great for them even to be tested. I learnt of a sibling's deep distress at not being a match, which increased at the death of the patient, as her belief was that she would have saved her sister if only she had been a match.

The teenage cancer unit has expanded since opening in 2004, and now includes young adults up to the age of 25 years, so the name has been changed to the teenage and young adult cancer service. The number of bone marrow transplants has doubled as a consequence. The work that I previously undertook with a single colleague has gradually grown and expanded to become a psycho-oncology team that includes psychotherapy, psychology and psychiatry. It is unique in this respect, with no other team including all three disciplines in the country. There are two main hospitals close to the city where I

work – including the one where I am employed – that offer a dedicated teenage bone marrow transplant service.

As with Patrick (1973), living with the ‘gang’, as it were, had its drawbacks. I knew most of the families that I approached for the study. I decided to gather my participants from the hospital where I was employed in part as a practical measure, since I worked full-time and travelling to another site would have cost valuable hours. The advantages were that I was in daily contact with my medical colleagues, and I felt steeped in this world of transplants and their impact on families. This enabled me to recruit participants more easily. I also considered the fact that as a child psychotherapist in this unit I had rather a unique role. It might have been more challenging to approach another site for my research, but since my role as a child psychotherapist in this hospital was understood, it meant that recruiting participants was welcomed and therefore more straightforward. The disadvantage of recruiting donors from my own workplace was that I came to the interviews with some knowledge of the family in my mind. This knowledge, however superficial, may have prevented me from asking some questions I might have automatically asked had I not known the family circumstances.

3.7 Selection of the sample

The original study was designed to explore the emotional impact on sibling bone marrow donors in three separate groups:

- Prospective sibling donors whose recipient sibling was about to have a bone marrow transplant
- Siblings who had already donated and whose recipient sibling was well
- Siblings who had donated but whose recipient sibling had died

As the initial work in the recruitment of participants was undertaken, it soon became clear that it would not be possible to recruit prospective donors as participants, as families were too anxious about the preparations for donation to agree to participate.

I received no responses from the group of sibling donors whose recipient sibling had died when initial inquiries were made about their willingness to participate. I felt concerned for these families, but I also felt that the letter had been carefully

designed to explain what the study involved. I decided that an unsolicited phone call would be too intrusive and put undue pressure on grieving families. I address this concern in my conclusion.

The study methodology was therefore adapted to include only those siblings who had already donated and whose recipient sibling was well.

3.8 Recruitment, ethics and limitations

3.8.1 Recruitment

The clinical nurse specialist (CNS) within the medical team responsible for bone marrow transplants agreed to approach prospective families about the study. However, it soon became clear that families approaching this treatment would not consider joining a research project that needed discussion of their emotions, which at this time could have made them feel more vulnerable.

The CNS compiled a list of families where a sibling had donated bone marrow and the recipient had remained well, and where either the family had given explicit permission to be contacted by the CNS or me and that they would welcome such contact. I contacted these families by telephone, introduced myself, and explained my profession and role in the hospital and how I had their details. If the family agreed to hear more about the study, I described the main aims of the research. For the families that remained interested, it was agreed that I would send them by post a description of the study and a stamped addressed envelope with a form for them to confirm their interest in participating or their decision to decline (see appendices for these documents).

The open-ended semi-structured interviews (see appendix) were designed to consider three broad areas of the sibling donors' experiences: the experience of the decision to donate, their experience of actual donation, and their experience following donation.

3.8.2 Ethics

For all research that takes place within a National Health Service (NHS) setting, ethical approval must be obtained before any researcher can approach a patient or participant. Clear guidelines must be followed, commencing with an application online via the Integrated Research Application System. This system is for any research, including drug and treatment trials, and is a complex system

to navigate, particularly when the research is of a psychological nature and could take months to complete.

Once this is done, the research proposal and letters of invitation to participants, including a document clearly stating the purpose of the research, must be submitted to the National Research Ethics Service (NRES). I was invited to attend the committee meeting to answer questions about the research on 16 May 2011. My proposal was accepted in October 2011.

This overall ethics scrutiny took some six months, and resulted in procedures and protocols that I felt were as sensitive and balanced as possible. It was important and helpful to have the opinions of NRES, and meant that all participants were contacted in a way that was as sensitive to their situation as possible. A report on the progress of the study was required at regular intervals, and when the study closed NRES had to be informed.

I also had to present my proposal to the cancer research group, which included all the doctors and many nurses from the teenage and young adult cancer service. This was also helpful, in that once again it focused on the process of the research and its aims. This group welcomed the study and felt that it would be helpful to obtain an understanding of the donor perspective for the growing bone marrow transplant service.

This study was also my professional doctorate, and therefore ethical approval had to be obtained from both the Tavistock and Portman Trust and the University of East London, both of which supported the study.

Letters to the participants and the information sheets regarding the detail of the study are in the appendices to this thesis. All taped and written material was kept in a locked cupboard. All participants signed the information sheets to say that they had read and understood the purpose of the study, and that they were happy for their interviews to be used in this research study.

Finally, in writing this thesis I made every effort to maintain the participants' confidentiality by using false names and disguising personal details where possible, unless this would have compromised the data.

3.8.3 Limitations

My research was limited to five participants, a relatively small number. As already discussed, whilst this limits any confident generalisations, the number of participants allowed the generation of rich data and an in-depth of exploration of the impact of donation on each of these five sibling donors.

In this research into the emotional impact of sibling bone marrow donation, 'the case' could have been the whole family, including the recipient of the bone marrow. This would have captured the opinions of the whole family, offering views from different family members with their own perspectives on the how the donor had fared. As with any case study, there was an important and particular decision to be made about the boundaries of the investigation. As Yin (2014:65) helpfully writes: 'The point is that the needed adaptiveness should not lessen the rigor with which case study procedures are followed.' Moreover, had it involved the whole family, the study would not have been practically possible for me alongside a full-time job, and this awareness of my limitations also helped to shape the design of the research. I return to this later in the thesis.

3.9 Ethical issues during the research

Due to the sensitive nature of the research, I was prepared to offer to see the participants outside the research in order to offer psychological support in my role as a child psychotherapist if they were disturbed or upset by the process of recounting their experiences. The psycho-oncology team of which I was a member was also prepared to offer further support to any participant who requested it but chose not to have sessions with me.

The bereaved families did not respond to the carefully designed letters that I had sent, and I decided that it was not ethical to call or write again. However, there is an important question about how such families fare if the patient dies and contact with the hospital ceases. Whilst the psycho-oncology team offers bereavement counselling individually and in groups, these sessions rarely include the bereaved siblings, and it remains up to the parents to seek help either at the child's school or in their locality. We continue as a team to endeavour to address this difficult but important gap.

3.10 Data collection

Table 1: Participants' sex and age, and the period between donation and interview

Donor	Sex of donor	Sex of recipient	Age of donor at time of first donation (years)	Age of recipient at time of first donation (years)	Period between donation and interview (years)
Alison	F	M	17	15	5
Tammy	F	F	10	13	4
Farah	F	M	10	12	5
John	M	M	18	13	Current
Daniel	M	M	13	15	Current

A suitable time was arranged for me to meet each participant sibling donor. Each participant donor was interviewed once, apart from one participant donor who was interviewed twice and in his own home. All other participants were interviewed in the hospital. Interviews lasted one hour. Permission was obtained from each participant prior to the interview for it to be audio-recorded. All the interviews were then transcribed, apart from two that were unfortunately lost due to my inexperience.

I reminded the participants that I was interested to hear their story, but suggested that the interview begin with their description of how the decision was made about donation. I encouraged each participant to tell me about the actual process of donation and how they had felt since this donation. I also asked them to reflect on their thoughts and feelings about how the donation may have impacted on their relationship with their recipient sibling. Whilst I kept these key questions in mind, I also allowed for the spontaneous unfolding of their experience, in keeping with my clinical experience.

3.11 Defended subjects

Hollway and Jefferson (2000:59) write that the free association narrative interview (FANI) takes into account the 'defended subjects'. 'The answer is to be found in our theory of the defended subject in which the crucial motivation for investment in particular discourses is the need to defend oneself against feelings of anxiety.' Whilst my interviews were not based on a FANI method, I used my clinical experience in the interviews to judge whether to explore some of the points being made by the participant or where the meaning was unclear,

without allowing it to become a therapy session. I began each interview with a question: can you tell me how you came to donate to your brother/sister? This then led to the donation process, and finally what they felt after the donation was complete. I wanted the participant to feel able to bring their experiences to the interview, and so I felt that an open series of three questions would help. However, I had not ever recorded sessions before, and I was conscious of the presence of what I felt to be a third person, as it were, in the interview. I return to this in the discussion chapter.

Since I chose to use single interviews with my participants, and with the above limitations and warnings in mind, I adopted a 'thematic analysis' approach to analyse the interviews.

3.12 Thematic data analysis

Braun and Clarke (2006:78) call thematic analysis 'a foundational method for qualitative analysis'. They describe it as 'a relatively straightforward form of qualitative analysis, which does not require the same theoretical and technical knowledge' as other forms (Braun and Clarke 2006:94). They go on to describe how it can provide a 'rich and detailed, yet complex account of the data' (Braun and Clarke 2006:78). Although this is a popular form of data analysis, there is no set of rules to say how it should be used. Braun and Clarke also stress that the researcher should have a clear question before setting about gathering the data. The question that this thesis was asking — what is the emotional impact of sibling bone marrow donation on the donor? – was inspired by the comment made by the young woman who said that she thought she had shrunk in size because of her previous bone marrow donation to her brother. It seemed important to me to investigate further what the meaning was *behind* this comment.

Willig (2013) explains that thematic analysis can use a wide range of ways of gathering information about the research question, not only from recorded interviews but also from blogs or text messages, for example. These might allow a more holistic approach to a topic. Although a clinician new to research may find this a useful method, Willig (2013:65) also warns against 'a "shopping list" of "themes" which do not represent anything in particular'.

Braun and Clarke (2006) counsel that criticisms of this research method are that it can be seen as too vague, so a rigorous method and theory should be applied to the collection and reading of data. They suggest the researcher immerse themselves in the data, reading the data in an active way. Braun and Clarke (2006:15) also suggest that the researcher look for repeated patterns of meaning. However, researchers cannot free themselves from their theoretical background, and data is not just collected in an 'epistemological vacuum' (Braun and Clarke 2006:12). A researcher may be looking at a topic without having read previous research; an inductive approach would involve reading the data many times over to find themes.

I came to my research with the young woman who felt she had shrunk in my mind. My psychoanalytic background meant that I conducted the data collection with the belief that all human beings have a fantasy life, and I was moved by this young woman, who feared she had been permanently affected by donation yet was still prepared to donate again. I wanted to understand if this affected all sibling donors or not. I wanted to investigate the adolescent cohort of donors, for they were the patients I met in my work as a child psychotherapist. I had not read previous research, so I came to this work with my training and the experience of working in the hospital.

In order to understand the participants' interviews with as much rigour and depth of meaning as possible, I undertook the following six analytic steps for each interview transcript:

1. I read the transcript and wrote a list of five or six main themes from a holistic reading of the transcript. My intention was that these would remain brief but contain the first impressions of the interview.
2. I made a line-by-line reading, making detailed notes on the whole transcript.
3. I listened to the tape again to capture expressions in the participants' answers that had been lost in the typed transcript.
4. I had research supervisions that involved reading each of the transcripts out loud, followed by a detailed discussion of their individual content.

5. An independent reader, who did not know my view of the main themes, read the transcript as I had done in step one. This reader listed the main themes on one side of A4, and gave them to me so that I could compare them with my main themes and consider differences and how these might have arisen.
6. Finally I wrote out a list of the main themes arising and evolving from steps one to four.

I devised these steps in order that I would be as familiar as possible with the material from each interview. Reading the interview once it was transcribed enabled me to notice things that perhaps at the time of the interview I had missed. Writing up a psychotherapy session after the event often allows links to be made in the mind of the psychotherapist which were missed in the intensity of the analytic session. I then undertook a careful line-by-line reading, which entailed making notes. Underlining certain words or sentences allowed links to begin to be made. Listening to the tapes allowed expressions not captured on paper to be relived and understood again. All these steps began to create a rich and detailed picture of the interviews.

Supervision with my doctoral supervisor brought further insights which I had missed or not understood. It also allowed discussion about feelings that had emerged in me in the interview. This could then be developed and understood in relation to the participant's emotions connected to the donation.

Then a colleague, also a child psychotherapist, read the interview and listed the themes that were most striking to her. These were often similar and overlapping with mine, but on occasion a different idea might appear, which could then be considered in light of my understanding of the text.

Lastly, I distilled the interviews into a final set of themes that had emerged from repeated applications of steps one to five above.

Originally, I considered using discourse analysis as the method to understand my data. Barker et al. (2002:87) describe discourse analysis as looking for 'the repertoires of discourse that a speaker is drawing upon'. Discourse analysis would have been appropriate if, for example, I had requested that the sibling donors write about their experiences: then their choice of words would have

been important to compare and contrast. However, discourse analysis is more useful where there is a group of people who share certain beliefs and feelings and thus may use similar words and phrases. The adolescent sibling donors were a small number of young people; they did not meet as a group, nor was there a particular public voice for their situation. Thus I thought that thematic analysis was a more appropriate form of analysis to see if there were shared feelings, beliefs or ideas about becoming a bone marrow donor to a sibling.

3.13 Learning from the research, being in a different role and clinical considerations

One thing from which I learnt was balancing the role of researcher with that of clinician. As a clinician I had considerations linked to the individual and their needs. As a researcher I was endeavouring to understand the needs of a particular group, and had to focus on my research question. The research would eventually benefit individuals, but first I needed to understand what the group's needs might be.

My first participant was clearly deeply affected by the impact of donation on her relationship with her brother, and also its impact on her learning, which even five years later was still having an effect on her career plans. I would have conducted this interview differently had she come to the service as someone requiring emotional support. There would have been a more gradual unfolding of the issues, and I would have been working in the knowledge that there were further sessions to be offered. Indeed, it might have been appropriate to offer to work with her on a more regular and intensive basis. However, whilst I both offered a follow-up meeting outside the study and wrote to her thanking her for her participation and offering to see her again, she did not take up these offers.

There were times in some of the other interviews, which will be explored in more depth in Chapter Five, when perhaps I could have asked a little more, but I hesitated for fear of opening up too deep a feeling that could not then be followed up. For example, in her interview Tammy muddled her donation with contracting meningitis. Once we had understood the muddle I asked her if she felt she had become ill because of donating her bone marrow. She quickly denied this, and I found myself anxious about putting a thought into her head –

so I did not explore this further, as I might have done if I had had the 'permission' of a therapeutic contract of weekly or more regular sessions.

I interviewed all my participants at the hospital at their request, apart from Daniel. He was too young to travel to London alone, and it would have meant further disruption for his mother to bring him to the hospital for his interviews. It would perhaps have been difficult to interview Farah in her home: it might have prevented her from speaking as openly as she did. It may also have felt helpful to her to be on neutral ground, allowing her to speak freely and also perhaps to leave her feelings with me at the hospital. I found it more challenging to conduct the interview in Daniel's home than I did in the familiar surroundings of the hospital, where I had a little more control over the environment. I was invited to conduct the interview in the kitchen, and whilst we were largely left to complete the interview, there were several interruptions from family members, including the dog.

In conclusion, this research work presented me with new challenges as a practising child and adolescent psychotherapist. The first challenge was the research interviews. I felt very conscious of the tape recorder in the room, and also felt rather constrained by the 'task' of researching – I was very much aware of my personal fears of academic work. I wanted to conduct an interview without 'memory and desire' Bion (1970), as in my daily work as a psychotherapist I would approach a piece of work looking for the 'problem' or 'difficulty' that had led the young person to be referred to me.

In the next chapter I report on the data from the interviews, including extracts from the interviews with participants. The richness of their words and insights into being a sibling bone marrow donor will then lead on to the discussion chapter, which will examine the commonalities and differences in the themes gathered from these interviews.

CHAPTER FOUR: FINDINGS

4.1 Introduction

This chapter presents the findings related to the primary research question of this study: what is the emotional impact of donation on an adolescent sibling bone marrow donor?

The analysis of the interviews was undertaken in six steps (see Chapter Three). In this chapter I seek to represent the voices of the participants in as close a way as possible to their own expression of their experiences as sibling bone marrow donors. For each donor, I first give contextual information about four aspects of the donor's family and wider life experiences that influenced their experience of donating, as reported by each donor:

1. Family structure (parents, siblings, the donor's position as e.g. first, last or middle child) and any key events
2. The culture and ethos of the family
3. How the donor came to donate
4. The method of donation, and how many times they donated

In reporting the contextual information, I have been careful to balance on the one hand maintaining the donor's confidentiality, so that they cannot be easily identified outside the family circle, and on the other giving enough information to allow a fuller understanding of the donor's experiences.

Following the contextual information, I report the findings in relation to three areas of each donor's experience:

- The donor's experience of his or her decision to donate
- The donor's experience of his or her donation process
- The donor's experience of the time following the donation – not just the immediate aftermath, but the months and possibly years following, and whether their experience has influenced their lives in any way

Finally, I give a summary of my main findings in relation to the donor's experience in each case.

As a reminder to the reader, there were five donors: Farah, Alison, Tammy, John and Daniel.

4.2 Farah

4.2.1 Farah's family context

At the time of the interview, Farah was 18. She was about to sit her A levels, and it was five years since she had last donated.

Farah was about 18 months younger than her brother Tariq, to whom she had donated bone marrow. It was noteworthy that Farah never mentioned her brother's name. She also had a sister three years younger than her. At the time of donation there were only three children in the family. Mother and father were married, and went on to have two more children once Tariq had recovered. Farah's parents were of Arab origin. The children were all born in England but visited family in their parents' country of origin on a regular basis.

Farah had donated three times in total, at 10, 11 and 13. The first two donations were made under general anaesthetic, the last while she was awake. The latter was by apheresis, a method whereby the stem cells are collected through a line inserted into the donor's arm and connected to a cell-separating machine. This pulls the blood through a centrifuge, collecting only a specific quantity of white blood cells and stem cells and returning the rest of the blood to the donor over a period of about five hours. Her brother began to recover after the third donation, and continued to be well. He had had severe aplastic anaemia. The final transplant and donation took place in my hospital.

Whilst Farah had agreed to join the study, in her interview I learnt that it was her mother who had persuaded her to join the research, 'because she realised that... because I talk... tell her...' Farah had never spoken about her experiences, nor had she told anyone about having donated bone marrow to her brother. The family did not discuss the illness or her donation at all, at the request of her brother. He had told no one – not even close friends – that he was unwell, and his absences from school were all attributed to minor illnesses. The two children born after the transplant knew nothing of their oldest brother's

illness or Farah's bone marrow donation. The family culture appeared to be divided: mother and daughter talked of the recipient's illness, but no one else spoke of it. I address this in more detail below.

At the time of the interview Farah was about to take her A levels, but was also reconsidering taking further A levels which would allow her to follow her dream of becoming an engineer. This dream had been abandoned during the period of her brother's last bout of illness. The reasons for her revisiting this wish were not clear, although it was apparent that her mother was very supportive of her ambition.

4.2.2 Farah's experience of the decision to donate

Farah said that she had donated marrow twice at a large children's hospital. She explained that her brother had been ill for some time: 'Um, yeah, he'd been ill for two years and then he... they said it went away, but it came back... So it was about three years and that's when I donated.'

She did not recall any process of choice: 'I didn't think about it, I just did it.' She and her younger sister were both tested, and Farah was a 100% match. 'So it was decided that I would do it for him, instead of my younger sister.'

I commented on the length of time that Farah's brother had been unwell prior to the first transplant, and asked whether she felt this had had an impact on their relationship: 'Yeah, I do... Yeah, I think it had changed. I dunno, I think that it got harder.'

Later in the interview Farah commented that she felt that her younger sister had been 'so eager. She really wanted to be the donor. So when it came back she was only 50% and I was 100%, she was quite angry.' Farah felt that this had made her sister team up with her brother: 'So it was always like him and her were like a team sort of thing, cos I am in the middle, cos I'm the middle child.'

4.2.3 Farah's experience of the donation

Farah said that she had not felt at that point, when she first donated, that she was affected by the procedure, which was carried out under general anaesthetic. She explained that she donated three times: 'I didn't even see him when it was on... I think it was the first time... actually, because I donated three times.' (By 'when it was on' I think Farah was referring to her bone marrow

being infused into her brother.) When I expressed my interest in this, Farah said: 'Yeah. First I was 10, then 11, then 13. So three times that I donated to him. And yeah, I didn't see him after.'

Her memory of the procedure was that she went to hospital, donated and came home: 'I didn't even see him... all of them [donations], I just gave it and it was whizzed off to him.' Later in the interview she spoke about staying in hospital overnight on these two occasions with her mother, but having a general anaesthetic and just wanting to go home. She recalled someone telling her what would happen, but did not recall any play preparation for the procedure.

However, Farah spoke about her last donation, when a femoral line (a line situated in her groin to collect cells with the apheresis method) was used:

I just remember feeling really embarrassed about, you know, doing the operation, you know, I had just started going through puberty... and it was all really embarrassing sort of thing, you know, I had to do an operation, especially the one that was inserted here [Farah indicated the top of her leg]... I just remember feeling so embarrassed.

This was clearly a difficult and embarrassing procedure for Farah, especially at the age of 13. She said that it was preferable to being 'put to sleep... I never wanted to be put to sleep.' There was little sense that there had been a choice to donate: 'I didn't really mind... just go and do it and get out.'

4.2.4 Farah's experience following donation

Farah responded immediately when I asked if donating to her brother had affected their relationship. She felt that it had had a significant impact.

F: Afterwards? Definitely.

J: Really... That's interesting. Can you say more about that? What was difficult?

F: It just changed a lot, he wasn't there constantly.

J: Yes, of course, of course. So he was then in hospital for a long time, wasn't he, afterwards, I guess?

F: Yes. [She begins to weep.]

Prior to becoming a sibling donor, she had got on well with her brother: 'So we grew up together, so we were quite close.' However, after she became his bone marrow donor for the third time, their relationship deteriorated dramatically.

Farah spoke about her brother's constant admissions to hospital and the fact that he was very poorly: 'Yes, he was really... he used to go in for about six months and then... come out... and go back.' Both children had been in their adolescence during the third donation.

Farah explained that her brother would not allow her to speak of his illness or her donation. It was never discussed at home, except occasionally between Farah and her mother in private:

We never really speak about it.... It is like a taboo subject... we just don't talk about it... because none of his friends know. No one ever, ever knows... We just don't talk about... Because none of his friends know. He went to secondary school telling no one, no one ever knew... so even now, no one ever, ever knows... yeah, so he went through secondary school obviously not being there a lot, but no one knew, except his friend.

Farah's brother did not want to be seen as different. Only one of his friends knew of his illness. So Farah too was never allowed to speak of what she had done, and her absence while donating was attributed by the family to a bout of flu.

Most striking was her brother's response to his GvHD, which for him was very visible in the form of livid facial spots and swelling. He explained this by saying he had got sunburnt on the beach. I asked Farah if it had made her anxious.

In a way I kinda thought it was my fault... When I gave it to him and... because at first it was only his hair that fell out so I didn't think it would be... and then I gave him the stem cells, that was when graft versus host started... I did kinda feel, oh I did this to my brother.

Farah said that she then felt that the relationship between them just got worse. He blamed Farah for this difficult side effect of the transplant, telling her 'you made my face go like this.' He also blamed her for his weight gain due to the steroids used during transplants, telling Farah 'you gave me your genes.' She

told me that he had been slim and sporty prior to the transplant, whilst she was not sporty and she felt she was fat too: 'like he gained weight because I gave him stem cells. I remember that quite clearly.'

Farah said that having to donate three times made their relationship more and more difficult. She said she had felt unable to tell anyone about what he had said to her, or to explain the hurt and worry that she felt. Farah was clearly deeply upset by these accusations, as well as by the imposition of a ban on talking about what had happened because her brother did not want to be seen as different from his peers. She considered that these responses and her sense of guilt had pushed them apart. She let me know that she felt it was her fault that it had taken three transplants before the treatment worked, and also that the horrible side effects her brother had experienced were somehow due to something contaminating inside her.

Farah attributed her slow deterioration in behaviour at school and her growing rebelliousness to having to donate her bone marrow. I asked her directly if she felt that being a donor had impacted on her schoolwork and friendships. 'I was extremely rebellious... I think I made some decisions that were really radical because I just sort of wanted to be... oh, I don't know... it was attention seeking.' During the interview this seemed reasonable to me, but I sensed that in Farah's mind the need for attention had not been a reasonable response to her brother's illness and the inevitable strain on the family. Farah also seemed to have felt rather hopeless at this point: 'It was like the attention couldn't be on us. It was all on him and it just had to be that way. He was ill, you know. We weren't ill.' It was as though this passivity was part of the family dynamic and had to be accepted. Farah went on to explain that she did attempt a rebellion, but that she had suffered academically as a result.

Farah was able to say that she had been a very bright student and was often able to do well in exams, despite the 'negative attention... I didn't attend lessons, I used to bunk.' She said that her teachers had told her that she had only got through her exams because she was clever. When I asked if she felt things would have been different if she had had a different sort of attention, she was emphatic: 'Yeah, definitely.'

She spoke of the disruption to the lives of everyone in the family during the years of her brother's treatment until he became well. However, she agreed that now, some years later and as he was well, their relationship had improved.

Farah explained that during the very difficult period, with her parents' permission, she had returned to the country of her parents' birth to stay with family there. This was a place where she had holidayed as a child with her brother: 'Because me and my brother used to go on holiday a lot together, we used to go on holiday a lot.' Farah said that in her 'rebellious' state she had felt as if she could 'take on the world', so going back to a place about which she had good memories seemed quite natural. But she also said it was because it had been the place where she had her first relationship. I imagined that this had happened when she went back, but she explained: 'Oh no, because when I was 15 we started going out, it was when we were on holiday over there, so I think that prompted me to go and live over there as well.'

It was as if she had needed to return to a place of good memories, but also perhaps to find a place where she felt appreciated, not criticised by her brother for making his skin erupt or blamed for his weight gain. She said: 'I think that it helped me grow up a lot.' She studied there for a time, but after six months returned home, which she said cost her parents more money as they had paid for a year's education there:

I dropped out in December and then I came back and that was all the money wasted as well, they had to pay for a whole year and they wouldn't return that money so... so that was kinda a waste.

We returned then to her present situation as she prepared to take her A levels, and Farah referred again to her mother's offer to pay for her to take more A levels so that she could realise her dream career. She was trying to decide, in part because it meant taking on further study, but she was also conscious of the further expense for her parents: 'so what now, if I start it and drop out again?'

I had no sense of her parents being angry about her change of plan, but there was a sense of the weight of guilt about this in Farah. This was her perspective, and her self-blame seemed marked. My strong sense was of Farah having feelings of guilt and shame about the side effects of donation apparent in her brother: 'in a way I kinda thought it was my fault, I did kinda feel, oh I did this to

my brother.’ Farah wept again as we talked about the decision she faced about whether to take further A levels once she had completed her current set. When I acknowledged how hard it had been for her and asked if she had spoken to her brother, she replied, ‘I told him, but...’ and wept again.

Farah had not spoken of her donation to anyone apart from her mother. This was the first time she had spoken of it since then, and it was clearly an emotional experience. She wept almost immediately we began to speak of what she had been through. Farah wept again later in the interview, as described above, and when talking about the decisions she had to take about her future. When I asked if she and her brother had been close, she said: ‘Yeah, definitely, because there’s only, not like a big gap, it’s only two years. So we grew up together, so we were quite close.’ It was clearly painful for her to recall that closeness and its loss.

She was a quiet young woman, and whilst what she said was powerful, she did not appear to volunteer her experiences easily. She was succinct in what she said, and I was conscious that her presence was in part through her mother’s prompting. I asked Farah:

So with that in mind, do you think that if you’d had help, if you’d had more support, not from your family, because of course they were consumed with your brother who was very, very ill, but if you’d had help from our side, do you think that you would have been able to... would things have been different?

She responded, ‘I think yeah, probably, yeah.’

At the end of the interview I spoke to Farah about the ‘donation’ of her story to me and how important it was, but my sense was that she needed to tell it and get away. I offered to meet her again outside the study to offer ongoing support, but she declined the offer.

4.2.5 Summary of Farah's experiences

When Farah first donated, she was not aware that there was a choice for her about whether to donate or not. She said that the decision was made for her, and it seemed that the decision to donate in her subsequent donations happened similarly without discussion or her active consent, although importantly not against her will. However, Farah did feel that donating to her brother, especially in their adolescence, had had an adverse impact on their relationship, as her brother blamed her for all the unpleasant side effects he experienced. These included weight gain and painful skin eruptions on his face. It also impacted on her relationship with her younger sister, who wanted to be the donor but was not a full match. She was angry with Farah and sided with their recipient brother. Farah felt that her brother's unpleasant physical side effects were her fault. She reported embarrassment during her final donation, which took place when she was in her adolescence and while she was awake. Farah wept several times as she recounted her experiences.

Farah felt that all these feelings aroused in her had caused her to become 'rebellious', and this had led to her truanting and choosing to study abroad for a time. When she donated for the last time she missed some crucial modules at school, which then impacted on her final choices for A level. This also affected her choice of career, a fact that she was reviewing at the time of the interview.

The family had adhered to her brother's wish that no one should know of his illness or Farah's donation. The family themselves never discussed what had happened, although Farah did talk to her mother about her feelings. Farah's two siblings born after the final donation were unaware of their oldest brother's past illness and treatment. Farah agreed that psychological help at the time of donation might possibly have been helpful, but now, five years later, she did not wish to think about it further.

4.3 Alison

4.3.1 Alison's family context

Alison was 23 at the time of the interview, two years older than her brother, Jacob, to whom she donated bone marrow when she was 17 years old. She lived with her mother and stepfather, but had no contact with her birth father.

Both mother and stepfather were white British. The family were close and supportive, and in touch with the stepfather's family from a previous marriage. She had a stepsister from this previous marriage, two years younger than herself, with whom she had a good relationship.

Alison's younger brother had been diagnosed with severe aplastic anaemia, and after testing she was found to be an exact match. At the time of donation, Alison had been working for her AS level exams. Her education continued to be an important focus, not only for the family but also for Alison. Alison learnt to drive an automatic car so that she would pass her test more quickly and thus be able to drive herself to school. She had ambitions to become a doctor, and this was supported by her mother in particular. This continued to be an important part of her identity; at the time of the interview she was progressing through her training and undertaking a project which would further her knowledge of her brother's condition. Alison had donated once via apheresis.

4.3.2 Alison's experience of the decision to donate

Alison came to the interview declaring that her memory of the donation was poor. She seemed, however, to have an excellent memory, and spoke in detail about her experience. She recalled that the first indication of his illness seemed to come from an injury Jacob sustained at rugby. She recounted with some humour her initial thoughts that this might just be him overdoing things:

My brother had gone to rugby, and he got injured in rugby somehow, like, you know... yeah, they fight each other or whatever, and then he was taking quite a long time to heal... you know, he's a teenager so he used to sleep till like two o'clock in the afternoon, but he slept all day Christmas Day.

The injury did not heal, Jacob became increasingly lethargic, and the concern in the family grew. She recalled her mother's worry that the diagnosis would be leukaemia, and the relief when it was not. Alison later explained her mother's awareness of and interest in medicine: 'I always watched *Holby City* with my mum and things like that, because my mum's quite science-y and I think she wanted to be a doctor.' There was a period of weeks whilst they awaited a clear diagnosis and her mother and brother visited the hospital for tests: 'my life kind of just went on [laughs].'

It was apparent from her descriptions how important the family were to her, how they supported one another, and how her stepfather's family were a part of this support:

I think everyone was emotional from it, getting a bit raw, and my stepsister is quite an emotional person and she just set us all off, so I went round to my stepsister's mum's house and had like a sleepover with them, and I remember we got the diagnosis that day... and I remember us all crying... I went there [her stepsister's house] and then I think the fact that the family became very, very close, and since then my family is so much closer.

All Jacob's diagnostic tests were performed at their local hospital, and he was transferred to this hospital once the diagnosis was confirmed. I asked how it was to have the family separated in this way. 'Yeah, because one thing I was going to say was that I'm lucky to have two parents that could look after me.' Alison spoke of the importance of one parent looking after her and one looking after Jacob; on occasion they would swop. She also described how the family prepared themselves for Jacob's possibly long treatment.

She described not feeling any hesitation about compatibility testing, and said that her brother would have offered to donate for her if she had been unwell:

I was just thinking yes, I know, I'm fine, just get on with it, it's my brother, you know, I'd already signed on the dotted line before I had even gone in there because it's your brother, you'd do for your brother, he's family so... but like, it's your brother, and like, if it was me he would have done it for me, and if it was my mum I would have done it for my mum, I would have done it for any member of my family... I found out from my mum that I was a 10 out of 10 match and I just went woohoo! All systems go, let's get on with it sort of thing.

Alison declared she could not recall much of the preparation:

I was saying to my mum I wonder how many visits I actually had, and all I can remember is one visit where I must have... where they explained everything and said we go through the back and blah, blah, blah.

4.3.3 Alison's experience of the donation

Alison at my request told me about the G-CSF injections:

One thing I did was have the growth hormone injections to make the bone marrow spill out into the blood, and they were really good at that because they came to my school, because I said I didn't want to miss school, erm, and we had this nurse, there was like a medical wing bit because it was a boarding school, she used to come into my school at lunchtime... I had two [injections] but they were really quite painful, to the point where I had to take a day off school because it was like severe growing pain in your legs.

She said:

I can only describe it as growing pains, really severe ones so that my back and my legs, the tops of my legs were killing me, and I remember sitting in bed one day and being like, oh god [laughs], and it was like five injections or something like that, and it got worse as it went along.

Although I did not ask at the time, I wondered whether this period had been more difficult because her mother was with Jacob. She explained that the pains got worse during the course of injections. Whilst again Alison described this with some laughter, I also got the impression that this had been a difficult time for her. Alison endeavoured to remain positive: 'but then you kind of thought of the pain, it's because it's doing its job, so I was kind of, its spilling out so [laughs] they can harvest it!'

She explained that her mother and father swapped over at this point so that her stepfather stayed with Jacob and her mother returned home to be with Alison. This seemed very important to her, and I again wondered if the pain had been more intense because of the temporary loss of her mother:

I think my mum came home and my dad stayed because I was... because it's nice to have your mum [laughs]... Yeah, I just said ah, yeah, I'm in pain, but then my dad was really good because in the week it was still painful and the first time I had the injections in school my dad came and picked me up, and it was painful, and I was saying oh it's painful, and obviously your parents look after you and stuff, so I was looked after and things like that, and because I was like Jacob's lifeline I think... at

that stage I think I got more attention because it was like, because obviously Jacob was there, and my dad was like, we need to get you safe so we can help him sort of thing, so the other day I said to him, he made some sort of joke, about, about oh yeah, it's not like my life depends on you, and I was like, well you wouldn't be here if it wasn't for me [laughs], and my mum said he'll thank you one day but he's just not mature enough right now [laughs], so I was like ok then, fine, so I'm still waiting for a thank you!

It would seem that Alison suffered during the time prior to the donation, and there was a slight suggestion of resentment at Jacob's lack of appreciation.

Alison went on to speak about the detail of the donation. I had the sense that despite her laughter, it was also a difficult experience. Alison was at first told that she would have a general anaesthetic, and she once again pulled herself together to face this:

So I psyched myself up for going the GA [general anaesthetic] route, going into the pelvis and taking the bone marrow that way, and I said oh god, ok, that is probably the worst way, erm, compared to taking it out of the arm, so I thought right, ok, well, you know, whatever, I will just have to get on with it.

But then, because her brother became more unwell, the decision was made to obtain the bone marrow via apheresis. The change of plan meant that Alison was confronted with something else: 'basically the needle was that thick, so you need a local... and I've got the tiniest little veins ever, so they were collapsing quite a lot of the time.' Her arm immobilised following a local anaesthetic, she sat with friends for the five hours of the procedure: 'I sat with my boyfriend of the time and my sister, and we watched *Step Up 3* and they fed me grapes, because my arms were out like this and I couldn't move them [laughs].'

Later that day she was told she must do the same again the following day, as her marrow had not produced enough cells. 'Mum came out of Jacob's room and she was like, Alison you've only made 3.2, and I was like, oh no, so she was like, you've got to go back tomorrow, and I was like, oh god, ok.' The next day, she declared triumphantly, 'I made something well over 12 million!' In addition, she had to take magnesium because her levels were reduced by the

donation: 'my lips were tingling, erm...' After this, Alison went to watch her cells being transferred to Jacob via a drip. She described the moment as emotional for all the family present:

I said to my mum, can I go and watch the stem cells going into him? And she was like, oh yeah, come up, come up, and we all had a bit of a cry as that was going on and things like that.

It was as though this was an important part of the process, and in some way an acknowledgment of its importance and her role in it. At this point she added: 'and then he kind of got better... and then his counts came up again and again and we're like, wahey, it's worked, sort of thing! And then we had a scare with GvHD, erm, but that was nothing.'

By this time Alison had returned home and the family awaited engraftment (when the new blood cells are produced from the bone marrow transplant – it can take up to two weeks for this to begin). Jacob's return to health was relatively straightforward.

4.3.4 Alison's experience following donation

Alison went on to tell me about the wait for Jacob to recover. Her mother predominantly looked after Jacob whilst he was in hospital; Alison's stepfather remained at home with her. She spoke about how important it was to remain in her own home: 'When you are a teenager, you know, your Internet is your lifeline, and you know, I was still able to do all the things and go to all the places I wanted to go to.'

She was able to continue her studies, which also provided a distraction from the worry about her brother, and she was able to see friends as well as to continue with her ambitions to train as a doctor. This wish was supported and protected by her parents.

Alison explained that she was given news of Jacob's illness, treatment and condition in a truthful way. However, she said that she was only told as much as she needed to know, and she felt that this was very helpful for her maintaining focus at school:

So I just thought I'll wait for the news, you tell me... you kind of get into the stage where you think ok, deal with this, move on, next bit, so that's kind of how we just took it on the chin.

Alison was not cut off from the stress, but rather she seemed to adopt a pragmatic approach to it:

Yeah, just kind of got on with it and did the best you could at the time, but I like, it was very, you could just see that everyone was stressed, but at the time I was like, I can't let it get me stressed, because I had my exams, so in a way I think that's why my memory is quite sketchy.

She told me that being able remain at home with her stepfather was important:

I would have hated to have been on my own... I could have gone and stayed with my grandparents and things like that, but they just don't live close to my school... people in the family could still take care of what was going on, and it didn't have to be someone you weren't really comfortable with or you weren't used to seeing every day.

She explained that she did not look up Jacob's condition on the Internet, and only asked when she felt especially anxious about what was happening. Alison described herself as 'very close to my mum, so it was very weird not to be because I am completely like my mum. I am a mini-me of my mum.' It must have been difficult to be separated for such a long period of time. However, her resilience was evident when she explained that she was now much closer to her stepfather and that this had been a positive outcome. She explained, though, that at times it could feel as if 'you weren't living life, we just got on with it.'

Alison presented as a good-natured and resilient young woman. The support and general closeness of the family were important, and information regarding Jacob's illness was only given when she asked or as she needed to know. Alison herself seemed to encourage this.

Her mother also became ill during Jacob's treatment and had to have treatment at the same time, travelling to a nearby hospital:

As well my mum fell ill during that time as well... yeah, so that was kind of, and she found that out when she was actually in hospital with Jacob,

so then it was like worrying about two parents... erm, it was breast cancer.

Alison did not dwell on this, and it is possible that her parents again protected her from the full extent of her mother's illness at this challenging time. She quickly went on to say: 'so and happily we're all fine now, everything is fine.' She said later in the interview that her story was probably different from her mother's, and that her mother's account would be darker: 'she would probably tell me a few dark things that I didn't want to know.' She did not want to examine that any more closely.

Jacob made a relatively quick recovery, and Alison referred to a period of 'mollycoddling' when he was able to return home. She noted that her mother 'would only get farm meat... she would get him steaks and things like that.' She also said:

Yeah, so like, life is changing and things like that, like after we came out of hospital Jacob was quite like, not wrapped in cotton wool but mum was really, really worried about him all the time... only sort of three years post him coming out that she could start thinking, yeah, you're all right by yourself now.

She recognised her own use of humour as a defence mechanism and how this had helped her to concentrate on her studies and obtain a place at medical school:

Hey, hey you, remember, you wouldn't be here if it wasn't for me, and he sort of went oh! That silenced him, so! We have to joke about it in a way, for honestly the fact that if I hadn't been there we might have lost him is horrific, and you don't want to think about it, so it's good that we can joke about it now, but you do joke about it, because to be honest to go through that, you have to keep your sense of humour, and I do think that's one of the things that has changed me the most, apart from becoming more resilient in times when I feel uncomfortable and in times where I feel sad or something like that, humour is such a defence mechanism, and I think I built it out of that time, because I used to be quite shy before, and I became quite confident because medicine gave me the confidence, but just before I got into medicine I started, like, I

think my humour was coming out more, and I think I was dealing with my emotions through humour, so yeah.

Alison's mother and stepfather got married after Jacob and her mother received clear health reports. They celebrated Alison's 18th birthday all together. During the marriage celebrations, Jacob, who was the best man, made a speech in which he paid tribute to his mother and stepfather for their support during his illness. However, he made no mention of the part his sister had played in his recovery.

Oh no, he acknowledged my parents and what they did for him, but I'm still waiting for my [thank you]... Yeah, it's still raw in everyone's minds what we went through, because I spoke to my mum yesterday and she got a bit emotional talking about it, whereas me and my brother don't any more [laughs].

In contrast to this, Alison's mother did tell her that she had saved Jacob's life and spoke of her pride at what her daughter had done. There was nothing in the interview to suggest Alison held a grudge, but it did seem painful for her that her brother was still unable to do this.

Alison described her relationship with Jacob when they were children as them fighting like 'cats and dogs', but she considered that their relationship had improved and developed now that they were older. She described how Jacob now consulted her on minor medical questions, and she expressed pride that he could contact her in this way. Her choice of career as a doctor had been made before Jacob was diagnosed, but she had never quite imagined she would achieve this goal. I asked if her experience as a donor would influence her choice of specialism, and she spoke of her current interest in haematology. Alison also referred to her inner strength:

God, I am a lot stronger than I think I am, and I think that kind of means that I end up doing my AS levels even though my brother was ill... so you just think obviously I've got a lot of inner strength.

Finally, Alison said that whilst she had not needed professional support, she felt others might, especially those in single-parent families. She felt too that more printed information for donors would be helpful, and that it should contain only

the information that they needed and should suggest that they not go looking on the Internet. The sense of ongoing responsibility was evident, however, when she told me that two years after Jacob had been discharged from hospital he had become very unwell:

I guess there was one thing where two years after he's come out of hospital he went on a boys' holiday, drunk himself in an oblivion like they do on these lads' holidays, had eaten, like, McDonalds every day or every week or something like that, and ended up having a temperature of 38 degrees and things like that, and it was awful.

When I asked if she had been afraid he had relapsed and that a further donation would be required, she at first responded with a quick denial, but then said: 'then in the back of head you are thinking, oh god, we've been in this situation before.' She felt, 'I've got to keep myself safe, because if anything happens to me... I have researched that... you know, it can reoccur and things like that.' She had intended to donate blood recently but then hesitated, because 'I've got to keep it all for Jacob just in case, so I kind of feel like now I have to look after myself just in case... if anything happens to me, he could give me some bone marrow.' There was a sense of her always being in reserve now that Jacob had her marrow. Alison herself referred to being 'a bit of a backup system for him, and that he's a backup system for me, but obviously I wasn't the one that was ill, so I can back him up.'

4.3.5 Summary of Alison's experiences

Alison reported that she had not hesitated to donate to her brother, and that he would have done the same for her. She appeared resilient and had learnt to drive so that she could drive herself to school, as her education was important to her parents and her. She was happy to receive information on a need-to-know basis, and she did not attempt to research her brother's disease for herself. Alison could shift from a more mature position to a younger self, for example when she recalled the pain of the G-CSF injections. However, the latter allowed her to access the support she needed at that time, and her mother was able to return from her brother's hospital bedside to care for Alison whilst her father stayed with her brother. At other times she displayed great maturity and confidence.

Alison had chosen a medical career and felt that her experiences had helped her gain confidence. She had begun to research her brother's illness as part of her degree. She also felt that it had drawn her family closer. She described feeling like a 'backup' system for her brother, and said that he was also one for her as they now had shared bone marrow.

4.4 Tammy

4.4.1 Tammy's family context

The middle child of three girls, Tammy was 14 years old at the time of the interview. Crystal, to whom Tammy donated, was five years older than Tammy, and her younger sister four years younger. Her parents were married and together. Her mother was a white British woman and her father of Turkish origin. The family were close, and Tammy talked about how she felt she and her sisters were all treated the same and were 'spoilt'.

Her sister had leukaemia, and Tammy donated three times: once under general anaesthetic when she was 10, and twice by apheresis. Tammy's sister relapsed after each donation, and finally an anonymous donor was found. Her sister made a good recovery after this donation and remained well.

Tammy had been diagnosed with attention deficit hyperactivity disorder (ADHD), and had had a difficult time at school until she was 'statemented'. She continued to struggle with the academic side of her schooling, but was enjoying a hair and beauty course at college, which she attended weekly. She found it very difficult to sit through the interview and was constantly moving and fidgeting; it was hard to keep her attention.

The family unit was a strong one, and this was evident in Tammy's interview. She described family outings and Christmas on the ward with her sister and family. It was her father who remained in hospital with her sister so that her mother could be at home with the two younger girls. Crystal was very unwell for much of the time during this period, and the medical team feared for her life.

Tammy was anxious when she came to meet me, and I was conscious of her laughing a great deal. Despite the fact that she was sitting down, I felt she was constantly on the move.

4.4.2 Tammy's experience of the decision to donate

I asked Tammy if she had any memory of the experience when she first donated. Tammy replied: 'I remember going there with my mum and my auntie... I remember me and my mum playing on the bed... just making it go up and down [laughs]!' She said that she had known about the procedure:

I knew what they was going to do because they sat down and discussed it with me, like when I first had the appointment, and they sat and discussed it with my mum and that, and I said I wanted to do it because of my sister.

She did not recall any preparation for the procedure, and described 'the day I was going being a bit scared, but I wanted to do it because it was for my sister.' Tammy repeated this several times in the interview. She recalled her first donation at a large children's hospital when she was about 10 years old, her mother being with her and them laughing as they moved the bed up and down, but her memories were otherwise hazy. She recalled: 'they put two cannulas in me first... You didn't feel that because you had gas and air.'

She donated again shortly after this, and then again at 12 (nearly 13) at my hospital. Later in the interview, she referred to the decision to donate: 'I didn't have to think about the decision, my answer was straightaway yes.'

I asked her whether, if they had known about the anonymous donor first, she would rather have taken that option. She said: 'I would want to do it first.'

4.4.3 Tammy's experience of the donation

She said she was relieved to be at the same hospital as her sister, as it meant she was closer to her sister and father for a short period. Tammy recalled her third and last donation: 'I just wanted to hurry up and get out and tell my sister I did it for her.' She told me that after this donation she had visited her sister on the ward: 'me, my mum and my auntie, cos my auntie stayed over, as well cos she switched with me from my mum and my sister and that, and my dad was up and down – it was confusing!'

She described how her mother, father and auntie swopped around to care for her and her sister, which was what was 'confusing'. I had the sense of a determined but rather vulnerable girl confused by all the changes brought about by having a seriously ill sibling. She spoke a little of the discomfort of donating

under general anaesthetic the first time, describing waking up and finding it 'painful'.

She also described the final donation when she was in Year Six at school, aged 12: 'I had it in my groin... That was painful [emphasising]!' She had had to sit for six hours: 'I sat there, for six hours with that machine, didn't I?... Six hours, that was all [laughs]!' She said she managed by 'sending my mum up and down stairs to get me things!' Her parents were not able to visit often, because of the risk of infection. Tammy told me she did not worry about school: she was 'just worried about my sister'.

At this point, almost imperceptibly, Tammy moved to talk about her own serious illness shortly after her third and final donation. I asked if that final donation was more painful, and she told me:

I think that one because when I was in hospital I had a lumbar puncture as well... Yeah, cos they said I could get it again, so I have to go for check-ups and that, so that's why I have to stay out of the sun and wear hair extensions, so I have to be careful.

In the interview it took me some time to understand that she was referring to herself and not her sister. After several very confusing minutes, she clarified:

No, this was when I was in hospital with meningitis! My neck went to one side like this, for one week I had, like, headaches and my mum thought, oh right, it's just headaches, and I had an eye appointment to see if I needed glasses, and they were like, no, it's not her eyes, and like two days later I had a temperature of 40 degrees.

She described her terror and pain and how her mother had had to 'hold me down'. She spoke of screaming in pain, and of how the doctors had told her she would always have to be careful: 'It was like the same thing... I just have to be careful of germs and that now. They said to me, mum, dad, be careful with her because she, you know, she could get it again.' This mirrors what her sister would have been told in the months after her transplant.

Tammy made a full recovery, but as she described her own diagnosis of meningitis, which included a lumbar puncture, it sounded as if it was the donation she was speaking about. She compared her donation to the pain she

experienced while ill, and it took me several minutes to unpick my confusion. Tammy explained that her sister was terrified that she might have become infected with the virus, but fortunately this was not the case: 'But I wasn't allowed near Crystal for a whole four weeks. She was crying, oh my god, because it's contagious.'

Once I had understood the muddle, I asked if she felt that the donation had caused the meningitis. Tammy denied that quickly, and I sensed that this was not an area to investigate further in the interview.

My strong feeling at the time was that the muddle regarding her illness was a not a wish for attention or an attempt to be like her sister. It was more that it was hard for her to differentiate, and there was a theme of 'we-ness' or a merging with her sister that ran through the interview. She later said in a very genuine way that she did not blame her sister for rejecting her bone marrow:

I was upset that it didn't work but that's... I would never say Crystal, oh why didn't it work, because it's not her fault... I weren't mugged off or something like, but it's her body, it didn't retaliate so I just thought... I don't ever thought, oh what's the point of doing it, because it's for my sister, and sometimes I think I want to do that in life, like help kids and give them donations.

I felt at the time that this was protective of Tammy and allowed her not to feel hurt that an unknown donor had been successful.

4.4.4 Tammy's experience following donation

Tammy reflected that she would donate again to help other ill children, and now that she had 'done it four times' (including her lumbar puncture) it no longer worried her. Her family appreciated what she had done: 'Yeah, it made me be like, made my family feel like, I'll always be there to help them because I love them.' Tammy had had some very difficult experiences at school due to her ADHD and her impulsiveness, and the experience of praise and appreciation after donating appeared to be positive and important.

However, there was evidence too of continuing anxiety about the possibility of her sister's relapse or death: 'Yeah, frightened, just in case my sister did like... pass away. She did die with my mum, twice I think it was, but mum got her

there in time.’ The anxiety was evident too in her descriptions of her vigilance at home, insisting on locking the doors at night and checking internal doors were shut, as though to keep out any germs or contagion: ‘I can’t have the bathroom door open at night, I hate it... I dunno why, I just don’t like it! I don’t go downstairs at night [laughs]!’ The anxiety was persistent, as was evident in the following sequence:

T: When something’s wrong nothing gets it off my mind.

J: Nothing can distract you?

T: No.

J: Telly or...

T: No.

J: ...films or something?

T: No.

J: Right, ok. Gosh. So you must have spent a whole year and more just worrying?

T: Yeah.

It seemed possible that Tammy’s sense of ‘we-ness’ or merging might have made it more difficult for her to differentiate between her sister’s disease and her own – hence the confusion I experienced over the meningitis. There was further reference to her anxiety about her sister: ‘And we are waiting to have... I can’t think what they are called... grommets in her ears, she keeps getting earache.’ Tammy hoped that this would help her sister to not succumb to so many infections. However, when I continued to ask about her worries, Tammy began to give ‘yes’ or ‘no’ answers, and I felt that it was making her uncomfortable.

We turned instead to her sister turning 19. When Tammy told me about her sister’s birthday celebrations, I wondered if she hoped she would receive the same attention for her own birthday, perhaps underpinned by a feeling that Crystal got more because she had been ill. She rejected this idea: ‘No. It’s all the same... We’re all spoilt!’

I asked her about other areas of her life, having heard from her father that she had been bullied. Tammy spoke of this with some insight: 'It's not really bullying, cos I say things back!' She had moved to college for two days a week, training as a hairdresser, and this suited her better as she could be physically active. Tammy liked college 'because no one... we all get along in college. There's no arguing or nothing.' She identified one teacher in particular who was able to understand her, 'cos she is nice and she always says to me, like, I'm always here for you.' I suggested that it must be hard to have so much going on at home and to concentrate at school. She agreed: 'I found it hard having my mum and dad split apart. I like it when we are all together.'

As the interview concluded, I commented again on her family's appreciation of her, and she referred to a thank you card she had received. She was unequivocal about donating and clear that it had given her a sense of pride: 'I've already told my mum what I want to do in life, I want to help other kids.'

4.4.5 Summary of Tammy's experiences

Tammy did not hesitate to donate for her sister. She donated three times, and remained enthusiastic about it on the grounds that her sister was family. Family was of great importance to Tammy. There was a strong sense of 'we-ness' or merging with her sister and her family – so much so that when Tammy spoke about her own illness, meningitis, I was unable to distinguish that experience from that of donating. She described ongoing side effects that mirrored those of her sister's leukaemia. Tammy did not blame her sister, nor was she angry that all three of her donations had failed. However, she described anxiety in relation to her sister's health and in regard to feeling safe at night when at home – she needed all the doors upstairs to be closed. She continued to feel anxious about her sister's health. Tammy had had some difficult experiences at school, but becoming a bone marrow donor had been a good counterbalancing experience. She described great pride in what she had done and the gratitude she had received.

4.5 John

4.5.1 John's family context

The middle of three brothers, John was 18 at the time of the interview. He had been finishing his A levels when he was tested to see if he was a match for his brother Ben, who was four and a half years his junior. John's older brother, who was in his early 20s, worked long hours in hospitality, which included many weekends. John had plans to take a gap year in order to travel before going to university. John's brother Ben had CGD, which meant he was often unwell with recurrent infections that were difficult for his immune system to fight off. The condition meant that, for example, a common cold could easily have developed into pneumonia. His parents were together, and both were white British. John's family were close and supportive, and they had a good network of friends and extended family. John's mother had a blog about her youngest son's treatment and experiences, and the CDG charity were making a film of Ben's experiences. John was included in this film as Ben's bone marrow donor. At the time of the interview, John's brother had become unwell just as he was about to be discharged. There had been some concern, but he was now recovering and they anticipated his discharge in a few days. John had donated once under general anaesthetic.

4.5.2 John's experience of the decision to donate

John did not answer explicitly when I asked about how he and his other brother had been asked to be tested. He told me decisively about being a donor: 'Well, obviously I was happy to do it the very first moment I found out. I think I found out from my mother, she told me separately in a room, she said it across the table.' He told me that he had been surprised when the results confirmed that he was a 100% match, as he felt his older brother to be more physically similar to the brother who was unwell:

To be honest, I only really thought about the whole process of being a bone marrow donor and my brother's side of the whole operation, really actually properly like thought about it, tried to understand it completely, till about two months before – didn't like... I knew he had to have... I thought it'll be all right... I didn't realise, appreciate how much a big thing on Ben's perspective it actually was, so I knew we were going to be doing it but I didn't quite... I was busy at the time and Ben wasn't actually ill. He's always been fine, so it's hard to imagine him being so ill... from

my point of view, he's my little brother, he's fine... yeah, then I found out... um yeah, when we were approaching it... for my part, I didn't think... I always knew I was going to be a bone marrow donor... oh yeah, I'm going to be a bone marrow donor, tell people about it, but I didn't think about what it would actually involve, it didn't really bother me, I wasn't really worried or anything like that.

It was as though his mother had understood that he needed some space to think, and telling him with the table between them was symbolic of that wish, perhaps to allow him time to digest what was to happen. Even after having donated, there was a sense he was still in shock at the whole event. He said that part of his difficulty had been that his brother was not ill at the time of the transplant. I asked if his other brother had been disappointed not to be a match.

I think he was... he might have been a little bit actually... I don't know... I haven't really spoken to him about it, but he thought it would be him as well, because there are similarities and obviously he wanted to help out... I think he was a little bit upset, yeah.

He recalled very little of the process of testing.

4.5.3 John's experience of the donation

As John's brother was well, a decision had to be made about when the procedure would take place. This took into account both John's exams and his brother's, but in the end it was John's brother who opted for sooner rather than later. John said he was glad

to get it out of the way... because the longer you leave it, it's at the back of your mind, you know it's got to come and um, yeah, it has been a difficult year or so... not so much for myself but as a family.

This decision meant that John's plans to travel in his gap year had to be delayed.

John could not recall much about the preparation to donate: 'Um, no, I don't think so... literally, they gave me an injection about five minutes before to make the platelets come to the surface, something like that, but other than that...' He seemed relaxed about the actual procedure. He donated under general

anaesthetic, and had little to say about this except that he was 'on the list to do it again'. He was enthusiastic about the support he had received:

I did actually enjoy it a little bit... the whole thing, I enjoyed it... there was no point when I was a bit nervous... nothing... and the care everyone gave me was perfect, it couldn't have been better... everyone was really friendly, I was given my own toothbrush, toothpaste.

He was very positive about this part of the donation, but when I asked if he had seen the donation being given to his brother, the mood changed a little:

John: So literally they took it across and I touched the thing – it was still warm – and... horrible! [Laughs.]

Jane: Ooh! That sounds like the only bit that you thought ooh...

John: But I would have gone in... but I was asleep...

Jane: Strange to think of your own bone marrow there in a bag?

John: Yeah, science behind it all... incredible... it's amazing what they do... absolutely amazing...

He told me that he had just seen his brother and that he was 'as lively as ever, and actually today the nurses said he was allowed out today.' His brother was recovering fast and would soon leave the hospital.

4.5.4 John's experience following donation

John was clearly relieved to see and hear that his brother was recovering. He had planned to travel, and I asked if it was a relief to see him improve.

I mean, I know when I am away I'm going to be a bit ugh... although I know he's fine, he's going to be fine, um, I like the fact that I can visit him in hospital... when I am away... if I had known a bit earlier... before we started to work, I might have felt a bit guilty at myself... Probably should be at home, you know... yes... I think it's going to work.

I believe John's reference to 'before we started to work' was in relation to his bone marrow donation and the fact that his brother was beginning to show clear signs of recovery. His reply seemed fragmented.

I suggested that his brother had 'turned the corner just at the right point'. John was reflective: 'I haven't thought about that bit, really, that I should be at home.' I was anxious that my comment might have sounded rather pointed, and wondered whether he worried that he might need to donate further marrow. He agreed with this, saying 'yes' and then 'no'. He seemed to be struggling with feelings about whether to follow his own plans or remain at home to support his brother. He talked about using Skype but said he preferred email, as if seeing his brother might produce some internal conflict and guilt about being away. I asked him if he felt he might be called on again:

John: Yeah, well, no...

Jane: Or just to support him?

John: Yeah, support, he liked it when we went in, cos he's in a room with mum and [laughs] and if you are stuck in a room with one, with everyone, they like visitors.

He acknowledged that it had been important for his brother to have them visiting him, and part of his experience following donation seemed to be of continued responsibility and duty: 'The thing I could do when I'm away is Skype... it's a bit different to speaking in person... but I'm not really a Skype-y person.'

I asked him if he had been worried when his brother was unwell: 'We were expecting it, you know, obviously because of the chemotherapy he's got no immune system, which makes him vulnerable to infection... um... and the doctors told my mum that he might generate an infection from within himself.'

This led to an exchange about whether the experience of donation had changed their relationship. John at first did not think so, but then said:

I would say it definitely has. We've always been, like, yeah... no ... definitely, I don't know, I don't know why obviously but... um... I think it's more the fact that I'd like to see him healthy again sort of thing.

John seemed a little fragmented here again, and I wondered again about his wish to go travelling, which had already been delayed and reduced in length, and whether this had left him anxious about his decision. My sense in the

interview was of his conflict: wanting to do what he felt was the right thing, whilst at the same time feeling desperate to get on with his own plans.

A further factor in his experience following donation was his sense of the importance of his visits to his brother, and also the recognition that this was not so easy for his older brother, whose demanding job meant he had less time to visit. John agreed when I suggested that he had been a donor and been able to visit too, and he joked about coming in to visit because of 'all the food there... and to see mum', which he found a comfort.

The idea that donation had been a powerful experience for him made him thoughtful. He referred to the 'luck' of being a 100% match and commented that other families were still awaiting a donor: 'it's a really good thing to be part of, so I'd love to do it again.'

I reminded him about the aims of the study, and asked whether he had thought about what further support the hospital could offer donors. He responded as if I had asked about donors donating to an unknown person: 'for some random person... Um, I'm not sure how I'd feel about it to be honest... um... I can imagine that I would feel left out.' I tried to bring it back to sibling donors: 'it would be a sense of the family themselves. If it was me I'd keep in contact with the person I've donated to, I want to go and see how you're doing, are you all right.'

We returned to his brother's recovery and ability to leave hospital for brief periods. This seemed to lead John to reflect again:

When you're at work and like, oh I gotta go soon see if... is all right, when he had his chemo that was hard, when I knew he'd first started chemo and he was ill, and the thought of him waking up in the night and throwing up and his hair falling out and not eating anything, that was quite hard.

These more connected moments in the interview led to John feeling anxious again, and full of praise for the NHS:

I've got 100%, um, admiration of the NHS and everyone in it, I think you're brilliant, I completely trust what they do, so I know everything's controlled and it only takes five minutes to sit, if you go in a patient's

room for five minutes, you understand they're checking, asking if you're all right, everything they do... is brilliant!

Yet there was a negative: 'I was literally asked about 10 different times... They overdid it... well, not overdid it...'

I asked if the blog that his mother kept had helped: 'Erm... I think so. Um, it's been nice because the blog's done stuff like obviously, obviously more people have noticed and seen, loads of people at home have offered support.' He was less enthusiastic about the film, saying he was 'not a fan of the camera', but he felt that it had helped them as a family. He mentioned that the film company had wanted to film him

looking out of the window, looking out over the top of London, as if I'm deep in thought, really emotional, on the edge [laughs]. I didn't enjoy that, that's not me and my mates are gonna see it and give me a rinsing.

I joined the laughter for a moment, and then suggested that perhaps the 'mindful' picture of him looking out of the window would be to indicate that 'some of it isn't easy.' This seemed to evoke a different thought, and I suggested that it seemed as if he did not have any especially difficult feelings about what had happened. He agreed, but then said: 'it's been difficult for my mum... my mum's story would be slightly different, but mine has been generally positive.' It also led John to think about when his brother would be 'released' from hospital and would have to 'make his way back to normality'.

The anxiety returned when John reflected on some of the restrictions that would apply to his brother for some months after his discharge: 'and stuff like his hair, they say it might grow back differently... there'll be a few other things like that... um.' When I asked what other things might happen, he did not continue but moved on instead to talk about how bored his brother would be at home, not allowed to go to school for two to three months. He yawned, apologised and said: 'he will get bored at home... I get bored at home if I am there for more than a day.' I wondered if John was defending himself from the painful thought of his brother bored at home whilst he travelled and then started university. However, I did not pursue this and in fact seemed to minimise it, asking: 'But those are the... the things, the only things that have been or would be potentially difficult?'

We were almost at the end of the interview. I asked if he had anything to say to other potential donors. He replied that he would recommend it to anyone. He had had lots of positive feedback from people: 'again, it's not really a big deal, other than that the better thing is the feeling I've got, like, yeah, I've helped him, it's a really good feeling.' I confirmed that he had had a positive experience of donating, but asked how it had been for him going to the teenage cancer ward.

Sometimes when you see other patients, especially our first trip to hospital, he had hair, he was fine, was perfectly fine, when you went in and you'd walk in and you'd see the other patients, myself, the way I felt was a bit like, without sounding really mean, like, oh god, you know... Ben probably felt a bit, um, I can't think of the right word to describe it, but he would've been probably a bit nervous maybe, I reckon that's how I might have, if it was me, oh god, like a bit worried about what is coming.

I wondered if this had been a shock for him. 'I wouldn't say shocking but reality check, probably. Yeah, reality check's the right word. Erm... I wouldn't say it's a problem because, yeah, reality check.'

When I asked if being a donor had brought some relief for his mixed feelings, he merely said 'yeah', so this remained less clear. This was where the interview ended.

4.5.5 Summary of John's experiences

John said that 'obviously' he was happy to donate to his brother, and that he had not thought about it until the time of donation. However, he was repelled by the thought of his 'still warm' bone marrow and could not watch it being transfused into his brother. He was worried about its impact on his recipient brother – how would his hair look, would it be different? He alluded to other possible changes in his brother, but did not say what sort of changes. There was a brief reference to the idea of a medical experiment, which was then firmly rejected.

John felt concern for both his brothers. He worried about his recipient brother, and also about his older brother, who he felt had to work long hours, and who was not a match despite looking very much like their younger brother. John felt his older brother might have felt left out.

John had to suspend his gap year travel plans in order to donate. Whilst there was no sense of complaint, there were anxieties evident as he prepared to leave. He did not wish to use Skype to speak to his recipient brother. John was proud of what he had done, and was on the bone marrow donor list for future donations.

4.6 Daniel

4.6.1 Daniel's family context

Daniel was 13, the youngest of three boys and the youngest of all the donors at the time of interview. He donated to his brother Michael, who was three years older than him. His oldest brother had autism, and his middle brother, Michael (the patient), had CGD. His parents were white British, married and together, and both worked in the medical profession. I met Daniel's mother on several occasions, but did not meet his father, who cared for Daniel and his oldest brother whilst Michael was in hospital. There was evidence throughout the interview of Daniel's and his older brother's need for their mother's attention, whilst their father was not mentioned. Daniel had ADHD and took Ritalin. I had had to interview Daniel before the transplant as part of my role as an assessor for the HTA, and separate permission was sought from Daniel's mother. Daniel was happy to meet me and said that he liked the meetings. I met Daniel once some three months after he had donated, and then again three months later. Daniel donated once under general anaesthetic.

4.6.2 Daniel's experience of the decision to donate

As the AA for the HTA, I had had to interview Daniel before he was allowed to donate, and to write a summary of that interview with recommendations. Daniel had understood all that was expected of him, and whilst he was to receive a videogame as a thank you gift from his mother, it was no more than he would have received had he been going to hospital for his own needs. He was happy to donate, because it was for his brother. He expressed no worry about the procedure, which was to be done under general anaesthetic because of his age and his ADHD. He asked if he might have a gas induction rather than a cannula with medication to render him unconscious, as this was what he had experienced for a tooth extraction. This procedure, whilst unusual for a child of this age, was used for Daniel's donation under general anaesthetic.

4.6.3 Daniel's experience of the donation

Daniel told me that he had been given gas to send him 'to sleep'. He said he had not been worried about this because of his prior experience with the tooth extraction. He had played a game with himself to see how long he could resist the anaesthetic and stay awake ('I'm not worried about going to sleep because I know I was anyway, but in the head, saying it's a game... just trying to stay up'), but he had discovered that it was 'impossible, basically'. I asked if he had worried he would not eventually go to sleep: 'No, generally I tried to stay awake because I knew I was going to end up [asleep].'

He recalled waking up as he was being wheeled back to his bed, where his mother was waiting for him. He felt weak but was keen to get up and move around, and the nurses and his mother had struggled to get him to rest:

I was half awake... my back hurt but... and I stayed in bed for another 10 minutes. But my idea was just to get up, I didn't feel... I did think I shouldn't get up because my legs would probably be feeling a bit weak but they didn't really. The nurse kept telling me to go back to bed.

I sought to explore his immediate response to the donation and whether he had immediately gone to see his brother in an adjacent ward: 'I first didn't want to but there were like a big... umm... a big like plaster on my back where it had two holes coming out... It wasn't like uncomfortable. It's like a piece of Sellotape on your back.' His mother stayed with him, he thought, because 'she had been staying with Michael the whole holiday.' It seemed that by 'the holiday' he meant his brother's admission to hospital.

In the second interview, John recalled the transfer of his bone marrow to Daniel as 'watching TV with my bone marrow going into him.' He referred to the slowness of the process, how boring it was, and his brother's lack of interest. He had not expected to 'see, like, it going into him'. I asked if it was 'funny' to think that he and his brother shared bone marrow: 'Yeah... a bit.'

Daniel told me about an incident that meant he had to have his blood tests redone:

They accidentally broke one of the blood tubes, and then it, like, it had gone all over the other ones. Then they had to redo the blood tests... but

I got to go in with the new, like, cancer unit place... I got to go on one of the most comfiest chairs.

Daniel seemed to have overcome any annoyance or upset he felt because he was given one of the best chairs, which perhaps allowed him to feel special and looked after. This aspect of his care seemed important to him. Further, he was enthusiastic about the room and bed that he had in hospital during the donation: 'I liked it because it was like lazing around, and mum let me use her laptop.' He told me with great delight that he could move his bed up and down: 'she'd come back in and it was up so I'd be the same height as her whilst lying down.' It was as though he felt rather superior and special, and indeed he described himself as feeling 'morality [sic] good'. There was evidence of envy too at the length of time his brother got to spend with his mother, whereas Daniel was only in hospital for a couple of nights before having to return to school: 'Yeah, I wanted to go back... Then I'd be with mum, [who] was basically like a servant, get me McDonalds, Burger King and all the snacks and food.'

He spoke of the large plaster over the two holes in his hips where the marrow was removed, saying with humour, 'I'm not sure that I've looked at my backside much but I don't think there is a ginormous scar across my back.' He was philosophical about the pain, but added that at least 'I did not wake up and feel I'd just been stabbed.' There is a possibility that in fantasy he had expected something quite horrible to happen, despite his good understanding of the procedure. He told me that he had thought of saying his legs were painful so that he could spend longer in hospital with his mother. This was his most difficult experience of the donation.

4.6.4 Daniel's experience following donation

When I interviewed Daniel for the first time after his donation, he told me that he had not thought about it much since we had last met: 'I felt sort of good, but not physically good... but in morality good.' As I explored this with him, he continued: 'I was a bit sick and I think I'm still a bit sick... a bit anaemic.' He told me that he needed to take iron and that he had forgotten his tablet that day. I asked if it had affected him in any particular way: 'Yeah... I think I've been worse in physical activities at school.' This was repeated in the second interview, with reference again to becoming anaemic. He said one of his friends had commented on it.

I hung back and he said that he thought I was looking a bit paler than last year. He said that how I'm a bit worse at swimming now, after, then I said because... then he would like say just... you appear to be really bad at swimming this year.

He had refused to take iron tablets at first because 'I generally find them to be a weird shape and it tasted really weird, so then I couldn't swallow them.' His mother (a doctor) had found a different brand that would be easier to digest. Whilst ingestion difficulties can be a side effect, I did also consider that the strength of Daniel's communications in the interview about this difficulty conveyed a sense of loss of his mother's attention, however much she looked after him in reality. There was evidence of his struggle then: 'I don't really mind I because... I know that when I take enough iron I'll get better... Like having CGD is worser than being anaemic because anaemia is more easily curable.' Daniel showed an important understanding of his condition, which was perhaps because it came from a less envious part of him. It may also have felt to Daniel as if donating his marrow had impacted on his body in a way that he had not expected. I return to this possibility in the next chapter.

Daniel also referred to other friends who knew about the donation and who 'thought it was pretty cool that I donated my bone marrow for my brother'.

He talked with passion about how difficult it was to have to come home after the donation and go back to school: 'I was the only person in the house that was going to have to do something during the day.' He tried to feel some sympathy with his brother:

I didn't like go and go oh poor Michael, I did a bit, but another part of me was telling me that he had tons of sweets and chocolate and snacks there, and he had mum there, and he had the new game and everything.

Daniel seemed able in the interview to speak in a direct way about his feelings. I got the impression that he and his older brother were both envious of Michael, his older brother was envious of Daniel's capacity to donate:

He doesn't really have that much input on it. He doesn't... well, he doesn't say anything about it. Generally he sees it as he would want to do the bone marrow transplant instead of me cos he would have mum for a bit, like, in the room with him too.

Daniel seemed to indicate that what all three boys wanted most of all was to be with their mother, who appeared to have all the food and treats they could ever need. He described having felt sorry for his brother when they were younger, but said they had then shared their mother's attention equally.

There was evidence of an expectation of appreciation: 'I don't regret donating, but I would have expected Michael to be a bit nicer to me. But I guess brothers... our older brother is saying... we're not exactly nice to each other normally. He annoys me.' I asked whether the relationship had got better or worse: 'Well I think it's been getting slightly worse but staying at the same level right now. But maybe I thought this because he stays inside the whole time.' He understood that their relationship had got worse when Michael was at home all the time, and he went on to say:

I don't regret it and I didn't expect there to be a change, but I still wanted to do it... I did think that, like, I might get more presents from mum and dad, but they gave me some... not really... I didn't really, like, see them but now with the stuff they bought for Michael, it makes me a bit jealous.

This seemed to indicate the complexity of the sibling relationship, which in Daniel and Michael's case seemed to involve a great deal of rivalry and envy. At the same time there was an important connection between the boys that allowed Daniel to donate and not to wish he had not. Daniel mentioned that the family – he said it was Michael – were currently involved in litigation against the local hospital, which had failed to diagnose Michael initially; Daniel told me that

Michael had promised to give him some of any money he might get from this court case. It was as though Michael also felt some gratitude to his brother, which although not actually confirmed and noted by either boy, was somehow present in the relationship: 'Michael is doing, like, the case and court about their not diagnosing... like, CDG. He said he'd give me some of the money for it, like, after I did it because of... I had done it for him.'

At the time of the second interview Michael was back at school, and Daniel felt much happier. He described them occasionally walking home together, as though equilibrium had returned. He talked of his birthday and how that had helped a little with his feelings of jealousy – he knew that he would get some special presents.

I had asked earlier if it was 'funny' to think that now he and his brother shared bone marrow. He had replied, 'Yeah... a bit.' Daniel said he had thought about it 'once or twice'. I asked if he and his brother had spoken about it, and Daniel replied: 'Yeah, only when I'm, like, joking. I say... as a joke, I might say... he is appearing more hyperactive now... I would say maybe you inherited it from me, as a joke.' Daniel said that his brother had replied crossly: 'No I'm not!' It made his brother cross, but occasionally when Michael was reprimanded for some misdemeanour 'a few times, maybe once or twice, then he said it's not my fault, it's his fault cos he gave me such a hyperactive immune system.'

I asked about his older brother:

He doesn't have much input on it. He doesn't... well he doesn't say anything about it. Generally he only sees it as he would want to do the bone marrow transplant instead of me cos then he would have mum for a bit in the room with him too.

I was struck by the rivalry between the three boys – boys who all have their special needs. The family had generally managed to negotiate this period well, and Daniel's honesty was rather moving. There was little mention of his father, although I knew that he had been at home caring for the boys during the transplant period. I asked Daniel about the meetings with me:

D: I don't mind these talks.

J: No? Good! You quite like it. Do you think these sorts of talks would be helpful for people who are donors?’

D: Hmm, well, yeah, because then you get information from them to give to other people that haven’t donated yet but are going to.

4.6.5 Summary of Daniel’s experiences

In the first interview Daniel was proud to have donated bone marrow to his brother and felt ‘morality good’, but he was also anaemic and felt that this had affected his ability in sports such as swimming. Daniel and his recipient brother used ADHD as something of a weapon between them: Daniel teased Michael that he was now more hyperactive, and Michael would say that due to the transplant he now had ADHD in his marrow, using this as an excuse when he was in trouble. Daniel was very jealous of the time Michael had had with their mother, and also of all the presents and food that he saw in his brother’s hospital room.

In Daniel’s second interview the most prominent feature was his envy of his recipient brother, Michael. He felt that Michael had had their mother all to himself, and that she did whatever he asked and bought him whatever type of food he wanted. He felt that she had been like a slave to Michael. He was relieved when Michael went back to school, because it meant that his mother was more available. Daniel still recalled the physical impact of the donation. He appeared to enjoy my attention, and his school report had improved.

4.7 Summary of main findings

4.7.1 Theme one: the desire to donate and a sense of ‘no choice’

The three eldest of the five participants (aged 13, 17 and 18 at the time of first donation) were adamant that they wanted to donate and would not have considered refusal. Tammy, who was aged only 10 when she donated for the first time, was not explicitly asked whether she wanted to donate, but made it clear in her interview that she did want to donate because it was for her sister. For Farah, also aged 10 at the time of her first donation, the choice to donate did not arise, as her family made this decision for her. However, looking back on the decision, Farah indicated that if she had been given a choice, she would have wanted to donate. Nonetheless, for all donors there was a sense of ‘no

choice', as the donation was for a sibling – for family – so that even without any external pressures, the internal pressure on siblings made it difficult to even contemplate refusal.

4.7.2 Theme two: 'qualified' altruism

For each of the five participants, their donation was not a completely freely chosen action but one made out of a mixture of love and duty. There was also an experience, and in some cases an expectation, that there would be some benefits to the donor. For Alison, it was her mother's gratitude; for Tammy, it was gratitude from the whole family; for Daniel, it was being close to his mother, improving his relationship with his brother, and hoping that his brother's legal case would lead to financial benefits for him too. With the other two donors it was less clear. For Farah, there was an implicit suggestion of appreciation from her mother. In John's case, whilst he had had to curtail his travelling, he was involved in the making of his mother's blog about the overall treatment, and this had resulted in positive feedback from readers.

4.7.3 Theme three: short-term physical and psychological impact

For all five of the participants, there were immediate physical and psychological impacts of donating. The physical impacts included pain from the G-CSF injections and anaemia. The psychological impacts included embarrassment due to a line being placed in the donor's groin, and anxiety about the physical process of donating (for example, the size of the needle used for the apheresis process) and the necessity for one parent to remain with the recipient in hospital.

4.7.4 Theme four: long-term physical and psychological impact

At the time of the research interviews, two of the participants (Farah and Tammy) had donated three times. The research interviews took place five years after Farah's last donation and 18 months after Tammy's last donation. For the other three participants the research interviews took place five years after Alison's donation, six months after Daniel's donation and three months after John's donation. For all five participants, there was a continuing experience of psychological impact, and in Daniel's and Tammy's cases some continuing physical impact.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

In this chapter I discuss the four main thematic findings summarised at the end of the last chapter. I will discuss the similarities and differences in the way each participant expressed their feelings in relation to each theme. I will then discuss how the findings relate to the literature. Recommendations for strengthening psychological support are presented in the next chapter.

5.2 Theme one: the desire to donate and a sense of ‘no choice’

5.2.1 Theme one summarised

The three eldest of the five participants (aged 13, 17 and 18 at the time of first donation) were adamant that they had wanted to donate and would not have considered refusal. Tammy, who was aged only 10 when she donated for the first time, was not explicitly asked whether she wanted to donate, but made it clear in her interview that she did want to donate because it was for her sister. For Farah, also aged 10 at the time of her first donation, the choice to donate did not arise, as her family made this decision for her. However, looking back on the decision, Farah indicated that if she had been given a choice, she would have wanted to donate. Nonetheless, for all donors there was a sense of ‘no choice’, as the donation was for a sibling – for family – so that even without any external pressures, the internal pressure on siblings made it difficult to even contemplate refusal.

5.2.2 Reflections on the data on the desire to donate and a sense of ‘no choice’

When I met Farah, it was eight years since her first donation, and so her memories were not clear, except that she recalled her brother had been ill for three years. When Farah told me that she would have wanted to donate if she had been given a choice, I was convinced by the tone of her voice, despite the long period of time that had passed. This determination was something I had also felt with other young donors. Farah said she had been close to Tariq in early childhood, and his long periods of absence may well have been difficult for

her as young child. Indeed, Farah wept almost immediately as she recalled her brother's absence: 'It changed a lot, he wasn't there constantly.' Farah was unable to verbalise further what feelings she had, but her tears were evidence of the distress she felt recalling the period in her life when her brother was unwell. I found this convincing evidence that for Farah it would have been impossible to refuse to donate, however difficult it might have been for her.

Farah recalled feeling embarrassed while donating at 13, as she had had a line placed in her groin to gather her bone marrow. I did not get the sense of a child or young person who had a desire as such to donate, but it did not seem as if Farah would have refused to donate to the brother she had been so close to.

Farah explained that the culture of the family was not to discuss Tariq's illness. Farah may not have understood why she was going to hospital, or even why Tariq was suddenly so absent.

In contrast to Farah, Tammy's mother had spoken to her about donating to her older sister, Crystal. It would appear that Tammy had been consulted about the possibility of being a bone marrow donor for her sister: 'they sat down and discussed it with my mum and that, and I said I wanted to do it because it was for my sister.' Tammy told me that she was 'a bit scared', but she was also unequivocal in her decision, saying that she did not have to think about it and that her answer was 'yes straight away'.

Tammy's recollection of these events was of playing on the hospital bed with her mother, which had been great fun. However, she found the third donation more challenging. Despite the fact that none of her donations was successful, when I asked Tammy whether she wished the anonymous donor had been used earlier, Tammy claimed she would still 'want to do it first'. Tammy's tone was strong and clear, as if there was no question in her mind and it was her wish, her desire even, to donate her bone marrow.

Daniel was 13 when he was found to be a bone marrow match for his older brother Michael. I had interviewed him in my role as an HTA assessor and Daniel had expressed no doubts about donating, stating that he was happy to do this for his brother. My impression was that Daniel was not concerned about the procedure and that he was genuinely comfortable with donating. The procedure had been explained to him by his parents and the medical staff.

My overall sense of Daniel's willingness to donate was that he was doing it in order to be close to his mother, and that the actual procedure was not concerning to him. However, because of the previous HTA interview I decided not to ask him this question again in the research interview. On reflection this was something of an omission on my part. Despite this I believe Daniel's first and foremost wish was just to be close to his mother, whatever the cost to himself.

Daniel did not speak of any feelings about his role as a donor, but he was very open about his envy and jealousy over the time his recipient brother had with their mother whilst in hospital. Daniel had ADHD and some mild elements that might be associated with Asperger's syndrome, and he played a game with himself to try to see how long he could resist the effects of the anaesthetic. This may have been part of his particular way of managing the world, a way of trying to control it. He described the fact that his mother had been with him and that she had left his recipient brother in the care of his father because 'she been staying with Michael the whole holiday' (i.e. Michael's time in hospital). He was pleased to have his mother with him, and was enthusiastic about the room and bed, which allowed him at times to raise himself up to 'the same height as her whilst I was lying down'. Daniel described his mother as being 'like a servant' to his brother. He enjoyed being with his mother, and was pleased to have some of the treats he believed his brother had had access to for the weeks he had been in hospital: 'she buys him a lot of things.'

Daniel's desire lay in his wish to be close to his mother, and it appeared that donating bone marrow to his brother was a way of achieving this. Thus in that sense for Daniel there was no choice. I was also convinced that whilst Daniel was jealous of his brother, he would not have wanted harm to come to him, and so, as with the other sibling donors, he would have donated his bone marrow.

Neubauer (1982:1) writes about 'rivalry' and indicates the importance of the rivalrous need, which may have felt to Daniel as if it was a matter of life or death to be close to his mother:

The original root of the term ['rivalry' is] 'one dwelling by or using the same stream as another' or 'fighting for the access to the river'... The

struggle is for the basic supply of the water for survival or, in our terms, for the mother's supply to satisfy basic needs.

Daniel described his brother's room as being filled with every sort of snack he could wish for, and he was quite straightforward about his own wish to stay in hospital longer after his donation for that reason. If he were to donate again he said he would pretend that his legs were more painful in order to remain close to his mother and all that she could supply.

Alison struggled with rivalrous feelings in relation to the pain related to the G-CSF injections. She needed her mother to return home to look after her, perhaps so that her mother would appreciate what she was enduring for her brother.

Alison and John were 17 and eighteen 18 respectively when they were asked to donate bone marrow. They both donated to siblings younger than themselves. Both were unequivocal in their direct assertion in the research interview that they would of course donate to their sibling. Alison stated that she had 'already signed on the dotted line before I'd even gone in there, because it's your brother, you'd do it for your brother, he's family.' Alison appeared to have a real desire to help her brother, although at the same time it was also as if there was no choice in her mind because he was her brother: 'I'm fine, just get on with it, it's my brother, you know.'

Freud (1990:295) wrote of Little Hans:

He was at the time in the jealous and hostile Oedipus attitude towards his father, whom nevertheless – except in so far as his mother was the cause of his estrangement – he dearly loved. Here, then, we have a conflict due to ambivalence: a well-grounded love and no less justifiable hatred directed towards one and the same person.

Neubauer's explanation of the original meaning of the word 'rivalry' gives a vivid explanation of the almost life-and-death struggle children might experience to be close to the mother and her supply not only of nourishment in the physical sense but also nourishment in the sense of her attention and love. Also in relation to rivalry, Freud here is exploring the effect of the birth of a sibling on a five-year-old boy. He notes the child's hostility to his father, who is not only a

rival but who has together with the mother produced another potential rival in the new baby.

Alison spoke honestly about how she and Jacob had fought like 'cat and dog'. Whilst this is quite ordinary for many siblings, the prospect of a decision over whether to donate takes this sibling hatred or rivalry to a more dramatic level. Alison may have felt unconsciously that refusing would mean the loss of the close relationship with her mother. Alison's 'desire' to donate may thus have been more complex than she indicated in her interview.

John also spoke as if there had been no choice in his mind: 'Well, obviously I was happy to do it from the first moment I found out.' John expressed no doubts, and was enthusiastic about the actual process of donation, which was carried out under general anaesthetic. He seemed determined to convince me that it had not been difficult, and emphasised that he would do it again 'right now'. However, John's determination was not as convincing as Tammy's, for example. This may have been because John had had to curtail his plans to travel as part of his gap year in order to donate his bone marrow. It may have been difficult for John to protest about the timing of his brother's transplant for an activity that could be viewed as self-indulgent in the face of his brother's continuing ill health. It would be hard to classify John's decision to donate as linked to 'desire', but like Alison he was old enough to be able to sign a consent form, and also old enough to understand the consequences if he refused.

John expressed some surprise that he had been a match to his brother Ben, because Ben looked so much like their older brother. John was concerned about his older brother, who he had believed would be the donor. I wondered if John had felt rather different to his brothers, that they were the 'matching pair' – hence his surprise to find that he was the match. Daune (2014:101) writes of how the family is 'under the microscope' when a bone marrow donor is needed: 'this somatic bond is sometimes very much different from the relation bonds within the family' (Daune 2014:102). When I asked if his older brother had been disappointed, John commented: 'he might have been a little bit, actually... I don't know... I think he was a little bit upset, yeah.' John also worried about his older brother because he was not able to visit as much as John did, because of constraints imposed by the older brother's employment.

Despite these varying statements regarding the donors' desire to donate, my overall impression was that there was little choice for these siblings but to agree to donate bone marrow. The family connection was of course an important part of this. In my clinical experience of working with families from a wide range of cultural and social backgrounds, it is common for families to feel that there is a social expectation for a brother or sister to help an ill sibling. However, and I will return to this, I believe that the sibling bond is so complex, especially during adolescence, that it would have felt impossible to refuse: doing so would expose ambivalent feelings that at their starkest might feel as if the sibling was prepared to sacrifice the life of their brother or sister. When it is regarded in this way, it is easy to see how little choice there is for sibling bone marrow donors.

The desire to donate is not spoken about explicitly in the literature as such. But with the participants in this study, the imperative of sibling status is paramount. As Alison put it, 'he's my brother, he's family, he would do it for me' – in other words, there is 'no choice'. Since there is no choice, there seems little place for desire to be possible.

5.2.3 The desire to donate and a sense of 'no choice' related to the literature

Weisz and Robbennolt (1996:389) point out that there are no medical benefits to a bone marrow donor, and medical teams must rely on the ethical justification that there is little or no risk to the donor. But Weisz et al. also suggest that the psychological needs of donors require further research.

The sense of an absence of 'choice' for the prospective donor emerges in the literature and is echoed in studies such as Weiner et al. (2007), Pentz et al. (2014) and D'Auria et al. (2015). Weaver et al. (2015) found that there was no choice but to undergo blood tests, and no choice but to agree to donate bone marrow if one was found to be a match. Biral et al. (2008) coined the phrase 'compelled altruism', which seems to encapsulate this familial pressure.

D'Auria et al. (2015:449) noted that participants felt they had to 'step up' because of the fear that otherwise their sibling might die: 'I just said "I hope I'm not the one that do my brother in. I just hope it ain't me." I mean... it would have been something man if it was me, it [would have] killed me' (D'Auria 2015:450). Even if the medical team have reassured the sibling donor that if the recipient

were to die it would be the fault not of the donation but rather of the strength of the disease, the possibility of a sibling's death may still be an enormous and terrifying worry for a sibling donor to carry. On one level this can be easily understood as an ordinary worry about responsibility for a sibling, but it is also readily understood alongside the research around sibling relationships.

Mitchell (2000, 2003) is clear in her extensive writings about siblings that 'sibling hatred is first and foremost' (Mitchell 2003:41), and she writes that there are murderous feelings for each other. This might explain the feeling of 'no choice': even if the murderousness is unconscious, to be faced with the thought that the death of a sibling might lie in the hands of the sibling donor would be very frightening for that donor.

Packman et al. (1997:251) note one donor in their study describing the procedure in the terms 'I felt like I was the one being violated.' Several sibling donors expressed the fear of dying during donation. It was as though in the donor's fantasy there was a choice to be made about who was to live and who was to be 'violated'.

To be faced with a choice about whether to rescue a sibling might almost feel like a terrifying enactment of a private fantasy, one which may involve a wish to be the parents' only child. If the brother or sister then becomes very ill, it may feel as if this wish or fantasy is coming true – 'that aggressive and murderous phantasies are powerful enough to become true and that she survived while her sibling did not' (Emanuel 2014:235). If a sibling feels as if their desire to be rid of the rival brother or sister has caused the illness, there may be 'no choice' but to try to save the endangered sibling.

Burnsall (2003:146) describes the siblings of children with acquired brain injuries as 'sacrificing', and links their actions with feelings of 'self-blame': 'Siblings placed their own needs, goals, and desires second to that of their injured brother or sister.' Part of the sacrifice might also involve demanding less attention from the parents, as in part the sibling feels responsible for the injury, however unlikely this is in fact.

Psychoanalysis addresses these fears with the theory of projection and projective identification, which addresses the way a feeling such as sibling rivalry can give rise to murderous thoughts. If that thought then appears to

become a reality (e.g. a sibling becomes ill or is injured in an accident), it can feel as if the rivalrous hatred has been projected into the sibling and has caused the illness. The sibling who had the thought will identify with the disaster and feel responsible, as if they have made it happen. I will address this theory in greater depth under my fourth theme.

My Sister's Keeper (Picoult 2004) is a fictional account of a donor sibling's attempt to refuse to donate a kidney after having already donated bone marrow on several occasions. Whilst only fiction, it does illustrate the feeling that refusal to donate might split a family. In this novel the donor's refusal is upheld in court, but the donor dies in a car crash on her way home, leaving the recipient free to use her dead sister's kidney. The novelist appears to have understood and perhaps described the unconscious murderous feelings experienced by both siblings, and how in fantasy one of the siblings must die because of these raw and powerful emotions. The phrase 'no choice' becomes more complex and yet also more understandable too.

Alby (1990), working with adult sibling donors, spoke of how rare it was for siblings to refuse to be tested for compatibility, because of their fear of revealing some 'dramatic conflict'. Daune (2014:109) also wrote of the complexity of sibling donation: 'Enmity between brothers or within the clan show how relations are both somatic and psychological, but on both levels it is a matter of life and death.'

Finally, it is important to also consider the more positive views in relation to sibling bone marrow donation. Fortanier et al. (2002) noted a sense of 'familial solidarity', and Switzer et al. (1998) in an adult study noted that sibling donors had a sense of 'life satisfaction'. Packman et al. (1997) noted that non-donor siblings showed more distress in self-reporting measures, which may link to the studies above demonstrating that sibling donors can feel some efficacy in a situation where a sibling is unwell.

5.3 Theme two: 'qualified' altruism

5.3.1 Theme two summarised

For each of the five participants, their donation was not a completely freely chosen action but one made out of a mixture of love and duty. There was also an experience, and in some cases an expectation, that there would be some benefits to the donor. For Alison, it was her mother's gratitude; for Tammy, it was gratitude from the whole family; for Daniel, it was being close to his mother, improving his relationship with his brother, and hoping that his brother's legal case would lead to financial benefits for him too. With the other two donors it was less clear. For Farah, there was an implicit suggestion of appreciation from her mother. In John's case, whilst he had had to curtail his travelling, he was involved in the making of his mother's blog about the overall treatment, and this had resulted in positive feedback from readers.

5.3.2 Reflecting on the data on 'qualified' altruism

Biral et al. (2008) used the phrase 'compelled altruism' in their work with paediatric patients affected by thalassemia. Many of these patients required more than one bone marrow transplant, and the team was looking not just at the medical aspects of this but also the psychological impact. This condition is common in the Mediterranean area and the Middle East. It can be difficult to find alternative donors to siblings. Biral et al. (2008) were aware that because of the high incidence of bone marrow rejection, bone marrow often has to be harvested from the paediatric sibling donor more than once.

The team managing these patients was concerned about the sibling donors, and described how they would involve the whole family 'in several sessions with the physician in charge and the clinical psychologist to discuss failure of the transplant and treatment options. In particular, the attention is focused on the donor's sense of guilt and responsibility' (Biral et al. 2008:380). The team felt that continuing to use sibling donors more than once had been justified, since the outcome for the recipients was eventually successful. However, it made their use of the word 'compelled' easier to understand, and also highlights the difficulty faced by these siblings and their families. It would have been almost impossible for the donors to refuse, since it would be difficult to find an unrelated donor of the right ethnicity.

I have used a different term, 'qualified' altruism, since I see this as a link with the sense of 'no choice' and as a development in our understanding of how sibling donors find ways to manage their feeling of being compelled to donate. Altruism is an act or deed that only benefits the recipient. All five participants donated their bone marrow to a sibling out of both love and a sense of 'no choice', but for three participants there was also an experience of gain.

Taking Farah's interview as a whole, I feel that Farah was still traumatised by her experience, although I cannot be certain. This may be the reason for her lack of recall of her first two donations, and her upset, which is clear from the start of the interview. There is a sense of 'no choice' in her description, but the fact that she endured a femoral line in her groin despite her embarrassment may also be seen as altruism. I was alerted to the idea of 'qualified' altruism by Farah's wish to return to her parents' country of birth, where she attended a private school paid for by her parents. She may have unconsciously felt she was owed this after all that she had endured, but she also spoke about her worry that her parents had paid for her schooling and that she had not done as well as she felt she should have done. At the time of the interview she was considering undertaking further study in order to fulfil her dream of becoming an engineer. Her mother had offered to pay for these extra lessons, and it seemed Farah was torn between feelings that she was owed this whilst at the same time recognising her mother's generosity.

Alison was brought home from school shortly after the start of her injections, and her mother left her brother in hospital in the care of his father whilst she returned home to care for Alison 'because it's nice to have your mum'. Alison laughed as she told me this, as though she could now see her infantile self and was a little embarrassed by it. However, because her mother and father were able to respond in this thoughtful way it had made the experience more bearable; it had not become a shameful or toxic memory. Alison was able to tell me and to laugh in a benign way at the memory.

Alison, her stepsister and her boyfriend, who supported her, all watched a film called *Step Up 3* during her procedure. This film depicts the rivalry between two street dance troupes. I wondered if Alison was unconsciously struggling to reconcile her rivalrous, angry self with a more benign self, the part of her that

was indeed 'stepping up' – being altruistic in order to help her brother. Alison had to donate further bone marrow the following day, and she recalled her feeling: 'I was like, oh god, ok.' Alison's bravery in the face of these procedures could be seen as altruistic, but at the same time there may have been an unconscious motivation too – to remain special in her mother's eyes. Later in her interview she described her brother thanking her parents publicly for supporting him through his illness but making no mention of Alison and her role in his recovery. Her wish for gratitude was understandable, and perhaps receiving a personal 'thank you' from Jacob would have made the memory of her discomfort more bearable.

Tammy's experience was complex: whilst she had been keen to donate, this must have been a very difficult procedure for a girl diagnosed with ADHD, who would have been unable to take her medication for a period before and during donation. Tammy described how worried she was about her sister, and there is a sense of her desperation to help her: 'I just wanted to hurry up and get out and tell my sister I did it for her.' I speculate here that this was perhaps the first time that Tammy had felt she was important and could offer something helpful. Despite the fact that none of her donations was successful, when I asked Tammy if she wished that the anonymous donor had been used in the first instance – saving her the pain and distress she had experienced – Tammy claimed she would still 'want to do it first'. Tammy was passionate in her wish to help her sister. There was a tone in her determination that struck me as brave and in many ways altruistic. Tammy, who struggled with ADHD and was often in trouble, had found something she could do that would inspire the approval of all her family. She described receiving a thank you card, which she treasured. It was as if the donation had allowed her to receive the approval and stature in the family that she had longed for. She explained that she would want to donate again to save other children.

John's mother began a blog to document her youngest son's transplant journey. At the same time the family agreed to take part in a film, which John explained was for the charity supporting people with CGD. Whilst John was not especially keen to be filmed, he agreed to it. I wondered if John had agreed to be filmed because perhaps unconsciously the filming in some way allowed him some celebrity status in this process of bone marrow transplant. In this way, because

of the supportive comments sent in response to his mother's blog, John and his older brother felt very much kept in mind by their mother, and also perhaps by other friends and family members. John had had to delay and shorten his gap year travel plans, and perhaps the filming and the blog allowed him to feel less disappointed. The sacrifices he made were acknowledged in the blog, which in turn allowed John to feel that his altruistic act was appreciated.

At first reading, Daniel did not seem to have altruistic intentions towards his brother. He was more generally consumed by jealousy at all the attention that his brother Michael received, especially from their mother. He was jealous of all the food and gifts he perceived were available to Michael. However, Daniel did suffer some physical discomfort, and whilst he could see that there was no actual damage to his body, he talked about a 'ginormous' scar on his back and the possibility of feeling as if he had 'just been stabbed'. From these descriptions I would assume that Daniel had had some fantasies about what would occur when he donated his bone marrow. Daniel was prepared to endure this if it brought him close to his mother. Later he described hoping that donating to his brother might bring them closer. This wish had not materialised, although the brothers would occasionally meet after school to share sweets. His brother had also promised him money if his legal case against his local health authority for a late diagnosis of his condition was upheld.

My theme of 'qualified' altruism is important here, and demonstrates again the dilemma faced by these young sibling donors. There is clearly a sense of 'no choice', but also perhaps some motivation to proceed because it holds the promise of gratitude, power (as with Farah and her parents), celebrity status or even financial gain.

I now look at what is said in the literature about altruism generally, and at how the word relates to what I heard from the five participants in my study. I will also explore how it especially relates to sibling bone marrow donation during the adolescent period.

5.3.3 The data on 'qualified' altruism evidence related to the literature

Mikulincer et al. (2005) carried out a series of tests with groups of securely attached and insecurely attached participants, first to assess attachment style and then to assess how each group responded to a situation where a woman

was shown to be in a distressing situation. Generally their findings were consistent across their participants that those who were securely attached were more inclined to compassion and a willingness to help someone in difficulty, especially if the participants were asked to imagine the subject as a member of their nuclear family. However they noted that there were some differences between nationalities and age groups, noting that the older Israeli students who had served in the army found 'pictures of accident victims and plunging a hand into ice cold water less disturbing than the younger generally more sheltered American students did' (Mikulincer et al. 2005:836). Whilst this might seem an expected result, it further demonstrates the sense of altruism as having both compelled and qualified components. John found himself confronted with the other patients on his brother's ward, many of whom would have had cancer. This graphic picture made John more sympathetic to Ben's possible feelings of fear.

Music (2014:45) also noted the link between altruism and attachment, and he felt that it was due to experiences within the family: 'Our best hope for being good to others in an empathic way comes from being given plenty of love, mind-minded attention and empathy.' For all five participants, there appeared to be good enough attachments within their families, enabling as Music (2014:43) proposes a greater degree of altruism because of their experience of a family who shared memories as well as hopes for the future – 'conceptualis[ing] oneself as part of a story with a past, present and a future'. There would have been some sense of duty implicit in this, as seen in Alison, Tammy and John's statements that they would donate for a sibling as a matter of course.

All the donor families were supportive and available in all five cases. Although Farah's family did not discuss what had happened to Tariq and Farah, Farah's mother had always been available to her daughter, and was the only one who knew of Farah's feelings. It was she who encouraged Farah to join my research, thus allowing her a separate space and some individual attention to discuss her experiences.

Bursnall (2003:147) looked at the siblings of children with acquired brain injuries and found that there was a realisation in the uninjured siblings that an accident

could also happen to them: 'I got a big fright. I had never seen anyone so sick before. But it kind of made me realize, because I am horrible to him sometimes.'

This led Bursnall (2003:156) to describe as altruism instances when the non-injured child placed their own desires second to those of the injured sibling. Such moments seemed to be due to a sense of self-blame. This appears to describe how children who are securely attached may feel able to be altruistic, as they are more likely to receive something back and may be more motivated to gain the attention and gratitude of the loved parent. This may motivate the child to greater acts of self-sacrifice and altruism. Alison addresses this: 'but like, it's your brother and, like, if it was me he would have done it for me.' Tammy too spoke of donating because it was for family, her sister; she also assumed it was what families would do for one another.

Bursnall (2003) also noted that the siblings in her study displayed similar caring behaviours to their parents, as though there was an expectation for everyone that the ill or injured member must be cared for. It may be that the attachment relationship, as noted by Music (2014), entails some responsibility for siblings, and that the children have learnt and absorbed how to be caring from their experience of their parents. There may also be a wish to gain or retain the approval of the parents, especially when much attention will have been given to the injured or ill child.

Gintis et al. (2003) acknowledge that researchers understand more about altruism in kinship groups, but they suggest that more attention is needed to understand guilt, shame and ethnic identity as related to altruistic acts. Whilst Gintis et al. are suggesting this in relation to non-related self-interested groups, I believe it would be helpful to look further at what motivates the paediatric population to perform such altruistic acts, particularly where these acts may be linked to feelings of guilt and shame.

These emotions, which are so bound up in the complexity of a sibling relationship, make it difficult to say whether a sibling bone marrow donation can ever be achieved without some degree of emotional coercion in the form of compelled or 'qualified' altruism.

5.4 Theme three: short-term physical and psychological impact

5.4.1 Theme three summarised

For all five of the participants, there were short-term physical and psychological impacts of donating. The physical impacts included anaemia and pain from the G-CSF injections. The psychological impacts included embarrassment (due to a line being placed in the donor's groin) and anxiety (for example, about the size of the needle used for the apheresis process, and also about the necessity for one parent to remain with the recipient in hospital). There was also a sense of pride, which had an immediate, short-term psychological impact.

5.4.2. Reflecting on the data on short-term physical and psychological impact

Alison had to have G-CSF injections to increase the marrow production in her bones. These were administered daily by a nurse at her school. These injections were very painful. Alison had to return home from school when the flu-like symptoms became too acute and painful, and it is possible that at this time Alison felt as if she was dying. It may be that a more frightening fantasy had intruded: that she was being sacrificed for her brother. I was reminded of Ishiguro's (2005) novel *Never Let Me Go*, which depicts a world where everyone has a live human clone who will 'donate' whatever body part is required by their matched human being. I had the sense that Alison had had to hold onto herself, not only during the actual event but also as she recollected these memories. Whilst she recounted the stories Alison laughed a great deal at herself, but this made me suspect that it had been more challenging than she was telling me. She laughed too as she recalled the procedure and how she had had to sit there all day, as the process can take up to five hours.

Farah's main memory of donating was from when she was 13 and entering puberty. She had a femoral line placed in her groin area. She recalled feeling 'really embarrassed', repeating this phrase three times, which increased my sense that it was still a memory that disturbed her. It had remained an embarrassment for her. Waddell (1998:127) describes puberty as a time when 'renewed conflict arises, for example between the conscious thoughts and the unconscious impulses attached to these new physical sensations'. Farah's embarrassing memory had a short-term as well as a long-term psychological

impact. Freud (1905:141) speaks of puberty as a time of reworking of infantile sexual impulses: 'The development of inhibitions of sexuality (shame, disgust, pity etc.) takes place in little girls earlier.'

Farah did not mention that she had experienced physical pain, but her memories of the actual donations were very brief. She may have pushed any such experiences from her mind, but I cannot be certain, and it would take some time for these memories (if any) to emerge.

Farah had also had to endure the fact that her younger sister and Tariq became in her words 'the pair', which was very excluding and difficult for her, especially as she and Tariq had been close before his illness. Most of the repercussions for Farah had long-term consequences, and will be addressed under the next theme.

In contrast to Alison, Farah's experiences would appear to be predominantly about embarrassment connected to the onset of puberty, alongside the upset she felt in relation to her brother and sister becoming close. She does not recall experiencing any pain during her donations. Alison recalls the pain of the G-CSF injections and her fear of the needles used in the donation procedure; this may be because she was older at the time of donation, and was perhaps more sensitive to pain. It is possible that her sensitivity was greater due to the absence of her mother, who was in hospital with her brother.

The main short-term psychological impact for Daniel was being separated from his mother while she was staying in hospital with Michael. This was briefly ameliorated during Daniel's stay when he donated bone marrow. He did not suffer much immediate pain post-operatively, although he had felt concern about the effects the operation might have on him. These fears were quickly settled when he awoke after the anaesthetic, and could have been addressed by better information. I will discuss this later in the recommendations.

When Michael had recovered and returned home, Daniel continued to find the attention his brother received challenging. Transplant patients have to remain at home for several months whilst their immune system gathers strength before they return to normal activities such as school or college. Daniel's mother remained at home with Michael. Daniel felt at times he was the only one who had to work: 'the only person in the house that was going to do something

during the day'. Knowing that his mother was at home with Michael all day whilst he was at school was very challenging for Daniel. He imagined that whilst he was away his mother would continue to give everything to Michael.

The psychological impact for Daniel seems at first to be in contrast with Alison and Farah, as his overriding feeling was jealousy. However, whilst neither Alison nor Farah named this feeling, there were elements of it for both: in Alison's need for her mother to return to look after her, and in Farah's jealousy of her younger sister and Tariq becoming close. It was important, then, for Daniel that I came to see only him and listened exclusively to his story. This did seem to make a difference, and his mother noted at the end of my second visit that his school report had improved. I cannot know if this was in part due to the attention I gave him, but I will address it in my recommendations later in the thesis.

John said he was not nervous at any point and that he enjoyed the process, describing how he was given his own toothbrush and toothpaste, as though comparing it to a hotel stay in his mind. He described waking after the anaesthetic as feeling no worse than a hangover, which may seem as if he was attempting to minimise the impact. However, for other donors this would usually signal an unpleasant reaction requiring pain relief and rest. John avoids giving any outward sign that donating his bone marrow was difficult, despite the fact that his travel plans were reduced and he had to manage his worry about both brothers. The only indication of any worry was the way his speech fragmented, for example when I asked if his older brother might have wished that he himself had been the donor: 'he might have been a little bit actually... I don't know... I think he was a little bit upset, yeah.' The impression was of someone who had managed well, with few short-term emotional or physical consequences. However, I shall return to the more profound impact donation had on John and the other participants under the next theme.

Tammy also experienced pain when she had to donate for the third time. However, Tammy also confused it with her own serious illness (meningitis), which I will address more fully under the next theme. She continued to experience anxiety with regard to her sister's health, even when Crystal had been discharged. Tammy felt anxious at night, and had to make sure all the

doors were closed in the house before she felt safe. Tammy did not outwardly appear to feel any upset that none of her three donations had worked for Crystal. She explained that she did not blame her sister for these donations not engrafting, saying that she was not 'mugged off... but it's her body, it did not retaliate.' This suggests anger, but in the interview I did not see this as conscious; rather it was Tammy's way of managing her disappointment. She went on to tell me that she would like to donate again to help children 'survive'.

On the surface Tammy was not upset. She was anxious, but she also felt pleased to have been able to help her sister and to receive the gratitude of the family. Tammy's own illness was a terrifying experience for her, but she muddled it up with her donation. Like Alison and John, she had been keen to donate as it was for 'family', but her enthusiasm was different: it appeared to be bound up in her desire to please her family too, in a way that was not present for any of the other donors. I shall explore this further under my next theme.

5.4.3 Short-term physical and psychological impact evidence related to the literature

There is plenty of evidence that the act of donating bone marrow can be a painful process. The pain is generally brief, and pain relief medication is always supplied. Parmar et al. (2003:92) was the only paper that I found that was written by a sibling donor: 'my initial reaction was to cry. The news was wrapped in much uncertainty and all I knew was that many needle sticks lay ahead of me.' It is an honest and helpful paper, as it addresses not only the fears of the sibling donor regarding the procedure, as explained above, but also the feelings of abandonment when the parents' attention is focused on the ill sibling.

Pot-Mees and Zeitlin (1987:80) reported that the sibling donors in their study needed to 'digest' their experiences but could not do so because of the absence of a parent, generally the mother. Alison spoke at the end of her interview about the need for more information and support; Farah also said at the end of the interview that if she had had some support it might have helped her; it appeared that Daniel found the attention from me enjoyable. It was less clear whether John and Tammy would have found it useful to have a space to digest the experience.

Packman et al. (1997:251) found that paediatric sibling donors felt that the medical procedures were like 'aggressive attacks on their bodies'. They wrote too of the sibling donors' fears that they would die during the bone marrow donation procedure. Alison's account of how her legs were 'killing her' and Tammy's muddle between donation and meningitis would suggest that they felt as if they had been attacked. Daniel was worried it might feel as if he had been stabbed. Whilst John said it all went well, he did mention the idea of a 'medical experiment', although he quite quickly denied that thought. Farah did not speak of it in this concrete way, although she felt it had profoundly changed her life.

Biral et al. (2008:380) comment on sibling donor safety, initially writing that there are 'no relevant side effects... except for self-limiting pain or stiffness at the harvest site'. However, later they write: 'Besides pain and anxiety, already described for adult sibling donors, in the pediatric setting, the issues are even more complex' (Biral et al. 2008:381). The issues of pain and anxiety are challenging in a setting where a bone marrow transplant would not be possible without the sibling donor. The pain and anxiety experienced by the donor siblings may appear preferable to the loss of the recipient, although this was not discussed by the five participants and I did not ask if it had entered their minds. However, that does not mean that it was not implicit in the request to donate bone marrow.

Weaver et al. (2015) also address these issues, noting the possible side effects of G-CSF injections, which include headaches, muscle and bone pain, and nausea. They also note the anxiety experienced by sibling donors prior to donation, generally related to the procedure itself.

The findings of each of these studies are consistent with my findings. Where my data extends them, however, is by showing the roots of complex reactions in age, personality and family structure

5.5 Theme four: long-term physical and psychological impact

5.5.1 Theme four summarised

Two of the participants, Farah and Tammy, had donated three times. The research interviews took place five years after Farah's last donation and 18 months after Tammy's last donation. For the other three participants, Alison,

John and Daniel, the research interviews took place five years after Alison's donation, six months after Daniel's donation and three months after John's donation. For all five participants, there was a continuing experience of psychological impact, and in Daniel and Tammy's cases some continuing physical impact.

5.5.2 Reflections on the data on long-term physical and psychological impact

During the course of my clinical work, a thoughtful CNS described to a prospective donor how she might go and watch her cells being transfused: 'you can watch you going into her.' This description seemed to suggest a merging of two people, which especially in adolescence may be experienced as having a sexual connotation, or may evoke a fear of loss of identity. It can also be seen as a concrete manifestation of projective identification as described by Klein (1988a:11): 'Projective Identification is the basis of many anxiety-situations, of which I shall mention a few. The phantasy of forcefully entering the object gives rise to anxieties relating to the dangers threatening the subject from within.' Klein was describing how we can rid ourselves of difficult, anxious feelings by projecting them into others, but that this can result in the fear of retaliation.

Farah's experience of donating to her brother Tariq was difficult and shocking. She moved from a sense of Tariq as a constant companion to a brother who was angry and blaming of her, despite her efforts to help him through her donation. She was not aware why she was donating, but nevertheless did as she had been asked. One of the most difficult side effects of bone marrow transplant is GvHD. The effects can vary in severity; in Tariq, his skin erupted in a red and painful rash. In particular it showed on his face, and he was furious with Farah, accusing her: 'you made my face go like this.' When Tariq gained weight due to the steroids he had to take, Farah understood this as her fault too. Farah described Tariq as always having been slim and sporty, and she understood he felt his weight gain had been caused by her and her 'genes'. Farah felt responsible for all these effects, and even for his hair loss: 'I did kinda feel oh, I did this to my brother.'

The psychoanalytic concept of projective identification, unwittingly paraphrased by the nurse's comment about 'you going into her', illuminates the power of

Farah's feelings. The concept explains how Farah may have felt as though she had poisoned her brother – that the GvHD was a sign of any angry, jealous or rivalrous feelings she may have had as part of an ordinary sibling relationship in the way already described. Emanuel (2014) writes of how the ordinary anger between siblings can become more toxic when a child becomes very unwell, as in Tariq's case. In fantasy the well sibling may feel as if they caused the illness.

Both Tariq and Farah were entering their teenage years at the time of Tariq's third transplant. Farah was emphatic that this last donation with a femoral line in her groin had been embarrassing. She had started puberty, so she may have been experiencing big changes, both physically and emotionally, at this time. Given Farah's description of her relationship with Tariq as close, Tariq's words of hatred and blame towards her must have been shocking. It appeared that Tariq felt contaminated by his sister.

The family's compliance with Tariq's request that his illness should never be spoken of may have meant that it began to be something shameful, a secret or skeleton in the family closet. Farah said that she became rebellious and did not do as well at school as predicted. It may have been that her feelings of shame – whether because she believed that she had caused her brother's GvHD, or because of her anger at feeling rejected by him – caused her to rebel and underperform academically. Rowe (2007:181) writes: 'When as children siblings struggle over who is the goodest and who has the power it seems to them that their struggle is a matter of life and death.' For a sibling bone marrow donor, this battle is taken to a more concrete level, and donors may perceive their marrow as the cause of the various form of GvHD – which is partly true. Farah may have felt as if she had actually damaged her brother.

It was at this time that Farah returned to the family's country of origin, the place where she and Tariq had enjoyed holidays together. Farah described how she had had her first relationship there, and I suspect that she needed to return to this first adolescent relationship in order to reclaim some sense of being important and attractive. She does not say so explicitly, but I suspect that it was also her first sexual experience, and perhaps an act of rebellion. I also felt that this relationship was important in terms of her internal world – her fantasy that she was toxic and the cause of the horrible effects of GvHD. She may have

unconsciously needed to introject something good and to feel desired. Bank and Kahn (1997:149) write of how siblings can influence each other in the way they approach sex and sexual identity: '[during] the consolidation of sexual identity – late childhood early adolescence – a sibling can tip the scales and seriously influence how an individual completes the resolution of his or her sexual unfolding.'

Farah remained abroad for seven months, and whilst she was in school during this time she never quite caught up with her peers. She was filled with regret and said she felt her behaviour had been 'attention seeking'. Once again Bank and Kahn (1997:149) note how an adolescent exploring their sexuality may be seen within the family 'as a trouble maker who, in the parents' eyes, may "contaminate" their younger children'. It may have felt for Farah as if she had contaminated her brother and perhaps her family, especially as Tariq's illness and her donation were not allowed to be spoken about. She felt as if she had caused Tariq's GvHD, and she spoke about how siblings born after Tariq's transplant knew nothing of his illness. It was as though it was a secret – something to be ashamed of that Farah could only talk about with her mother.

Alison's experience was different, in that her family did talk about Jacob's illness and the experience of Alison's marrow being transfused. She described the family weeping with emotion, but later in the interview a different feeling was conveyed. Alison spoke of an incident two years after Jacob's treatment had finished. He had taken a 'boys' holiday', returned with a high fever and had to be admitted to hospital. Alison was scathing about her brother, but had agreed to stay with him in hospital while he recovered so that her parents could continue to work. She was also a little triumphant. I asked if she had feared he had relapsed, and she quickly denied this, but then became more thoughtful and spoke of keeping herself safe in case he ever needed more bone marrow. Alison commented that now that he had her bone marrow, the reverse was also true and he could donate to her. There was a shared internal identity: Alison said that she was now a 'backup' system for him and he was one for her.

This was a very important statement from Alison. It suggested a more benign form of projective identification than Farah's, who felt her bone marrow was bad, toxic and harmful to her recipient brother. Alison seems to be an example

of introjective identification – an identification where a good experience has been taken in, become integrated, and can be retained as something helpful, as in the case of Klein's (1963:308) patient who 'had to some extent introjected the mother as a good object and had been able to achieve a measure of synthesis between his loving and hostile feelings towards her'.

Whilst Alison expressed her anger that Jacob had still not thanked her, she knew that her mother was 'eternally grateful'. For Alison, becoming a donor meant that she was able to save her brother, and thus to win the *eternal* gratitude of her mother and to achieve her mother's and her own wish that she should become a doctor. I propose that she had been able to introject enough that was good to counter the disappointment she felt at her brother's lack of gratitude.

Tammy had donated her bone marrow three times, but engraftment had failed. An unrelated bone marrow donation resulted in a successful transplant for Crystal. Tammy became unwell shortly after the third donation, and was hospitalised herself. When she was describing her final donation she moved seamlessly into an account of her own serious illness of meningitis. I became muddled at this point in Tammy's interview, and was unsure if Tammy was referring to the donation. When I understood that she had contracted meningitis, I asked Tammy if she had felt concerned that perhaps donating had caused this. Tammy denied this twice, and I had a sense that it would not be ethical to pursue this further without the containment of regular therapy sessions. Tammy instead turned the failure of engraftment on her sister, although she said that she did not blame her sister. This allowed Tammy to still feel that she had been helpful and that the family remained grateful to her.

Reflecting on this now, I think that Tammy may have had some anxieties about 'contamination'. Perhaps her painful experiences of donation and failures to engraft may have been the reason for the confusion between her donation and her illness. There had been a concern that Crystal might contract meningitis from Tammy.

Tammy had been diagnosed with ADHD, and had often been in trouble at school. Her delight at being a match for her sister may have resulted from the feeling of doing something worthy of praise. Tammy's marrow did not engraft

and an unrelated donor was found. Tammy said she did not blame her sister, explaining that her body did not 'retaliate'. I did not question this word, as I assumed she meant 'respond'; however, perhaps her fear was of retaliation, and meningitis was a part of this terror.

Waddell (1998:214) writes: 'The texture of a person's experience is made up by a constant interplay between... projective and introjective mechanisms'. As Waddell describes, these mechanisms change constantly. Tammy had introjected a sense of having something helpful to offer. After three donations this sense appears to have changed into feeling as if she had in fact projected something contaminated and unhelpful, even dangerous. Tammy remained anxious, and at home had to keep all the doors shut at night, particularly the bathroom door. I speculate that the sense that she had projected something bad into her sister and the fear of retaliation were an unconscious and frightening presence for Tammy. She said that nothing could distract her from these fears.

John, like Alison, was clear that he had wanted to donate bone marrow. John and Tammy both commented that they would donate again, but this time to unrelated recipients. John had not believed that his brother Ben was unwell. He had felt that Ben might have been 'winding him up'. His remark brings to mind teasing, which is often a part of an ordinary sibling relationship and can be a vent for angry or envious feelings. He was also surprised that he was a full match for Ben, despite looking very different from both his brothers. His plans to travel had to change, but he claimed he was happy to donate his bone marrow. However, once he had donated, he saw his marrow and touched it – it was still warm from his body – and was utterly repelled. He did not wish to see it being transfused, and told me he was asleep when it happened. I wondered if he needed not to be conscious at the time of this donation of body fluid – of 'going into him'.

Later he was disturbed by Ben's unwellness post-transplant. He was shocked, and explained that he visited often, partly to reassure himself but also to cheer Ben up. He spoke about Ben's hair possibly growing back differently: 'there'll be a few other things like that.' The doctors had told him that Ben might 'generate an infection from within himself'. The anxiety that John felt at times in the

interview was shown by his speech becoming fragmented, for example when we spoke about his plans to travel now that Ben was recovering: 'um, definitely, definitely... I mean, I know when I am away I'm going to be a bit, ugh... although I know he's fine, he's going to be fine, but um...' John may have felt in fantasy that he had contaminated Ben – projected his anger or resentment – hence Ben's response to the transplant, his hair loss, his sickness and perhaps even the possibility of his hair changing, as well as other unspecified changes. John declared that whilst he was away he would not use Skype because if he did he would be able to see his brother; he said, 'I'm not really a Skype-y person,' but it is possible that John was afraid of what he might see in Ben.

These hypotheses of contamination are consistent with Weaver et al. (2015:2): 'A poor or burdened medical outcome for the patient, including graft-versus-host disease or death, has consistently proven to increase risk to the psychological health of sibling donors.' It would be quite understandable for John to feel shock at the sight of his brother so unwell, and perhaps to make the connection in his mind with the warm, repellent marrow.

When I met Daniel after he had donated, he said that he did not feel well physically but he felt 'morality good'. Daniel had become anaemic. I felt that he enjoyed the attention, even when his friend told him he was now not so good at swimming: it seemed as if it had earned him the attention of his mother. It may be that having donated his bone marrow, and having witnessed the attention given to his brother whilst he was in hospital, Daniel felt depleted not just physically but emotionally too. This is again consistent with Klein's (1988a:9) description:

The projection of good feelings and good parts of the self into the mother is essential for the infant's ability to develop good object-relations and to integrate his ego. However, if this projective process is carried out excessively, good parts of the personality are felt to be lost.

Daniel's anaemia and loss of swimming prowess were a consequence of his donation. This was true in a medical sense, but in fantasy it may have been more linked to having donated (projected) his good marrow into Michael, his recipient brother.

Daniel described how he would tease Michael after the transplant, accusing him of appearing 'more hyperactive', which would enrage Michael. However, Michael in turn would use this possibility in his favour when in trouble, claiming it was not his fault as Daniel had passed on 'such a hyperactive immune system'. Again, this interaction can be explained by projective identification: Daniel had donated bone marrow to his brother, and they both felt as if it had altered Michael in some way, even if in part this was said in jest.

However, Daniel's school report was better than it had been previously, and whilst I was not able to discuss this with Daniel's mother, it may have been that the research attention he received from me, and his status as a bone marrow donor, had actually helped him to feel more appreciated, perhaps in a similar way to Tammy.

I concluded from the interviews with the five sibling donors that there were long-term physical and psychological impacts. Alison felt as if she remained a backup for her brother. She awaited his recognition for what she had done. Farah was attempting at the time of the interview to decide whether to embark on further studies which would enable her to study to become an engineer. She remained upset by the memories of Tariq's GvHD and her belief that she had caused this. Tammy remained anxious and vigilant, not only generally but also about her sister's health. John feared the long-term consequences that his donated bone marrow would have for his brother. Daniel struggled with anaemia, but was also concerned about the effects of his ADHD on his brother, and wished for a better relationship with his brother.

Klein's theory of projective identification explains the intensity of the feelings expressed by these siblings in their interviews. Whilst their responses were different, there were long-term consequences which Farah and Alison continued to feel, five years after their last donation. Tammy, John and Daniel were closer to their experiences, but were still profoundly affected by them. Given the longevity of sibling relationships, it seems important that psychological impacts should be attended to as part of the overall recovery of the whole family, not only that of the ill member.

5.5.3 The long-term physical and psychological impact related to the literature

Wiener et al. (2007) acknowledged the group of siblings who may be too anxious to undergo blood tests for tissue typing. The same authors later identified the phenomenon of sibling donors' 'guilt' in relation to GvHD or disease relapse in their recipient sibling (Wiener et al. 2008). Pain, discomfort and fear of blood tests or procedures have also been noted by Pot-Mees and Zeitlin (1987), Fortanier et al. (2002), Parmar et al. (2003), Biral et al. (2008) and Weaver et al. (2015). These side effects are not long-lasting, and although anaemia can follow a bone marrow donation it is successfully treated with a course of iron supplements. However, psychological impact is referred to by Pot-Mees and Zeitlin (1987), Danion-Grilliat (1994), Weisz and Robbennolt (1996), Packman et al. (1997), Fortanier et al. (2002), Wiener et al. (2007, 2008), D'Auria et al. (2015), Weaver et al. (2015) and McDonald et al. (2015).

I also looked briefly at the literature regarding the impact on children whose sibling has cancer or a chronic illness, and almost all work here noted a psychological impact. For example, Sharpe and Rossiter (2002:11) spoke of how siblings of children with a serious illness are in danger of 'internalising their difficulties'. Alderfer et al. (2010) investigated post-traumatic stress in these siblings and felt that there was enough evidence of it to warrant further research. McDonald et al. (2015:339) looked at the distress in adolescent and young adult siblings of people diagnosed with cancer, and noted in their conclusion that 'variables such as family structure and country of birth of parents have no impact on distress or unmet needs, indicating that all family types are potentially in need of support.'

I also looked at psychoanalytic theory in order to help me understand the meaning of donating bone marrow in the context of the complexities of the sibling relationship as viewed through psychoanalytic literature. A particular feature of donation is the transfer of body fluid from one person to another and the meaning of this when it is to a sibling, especially in adolescence. In summary, my data showed that there were fears about what had been 'donated' along with the bone marrow. Alison felt as if she was now like a backup system. Farah felt she had caused GvHD, and also that perhaps in a different way she had lost her ability as a good student and become a rebel. Tammy became unwell after her last donation, and there was confusion in her mind about the causes of her illness; she remained anxious and vigilant. John feared what he

might see if he Skyped his brother, and mentioned changes in his brother's appearance which he feared might occur. Daniel felt he had become anaemic and not such a good swimmer as he had been prior to the donation. He had hoped for an improved relationship with his brother, and he thought that his brother might have received some of his ADHD during the transplant. In many respects this confirms much of the literature already discussed. However, the existing literature does not look at the psychological impact of donation by taking into account the deep complexity of the sibling relationship as seen through a psychoanalytic lens.

Building on the work of Freud and Klein, other psychoanalytic writers have developed a conceptual understanding of the complexity of the sibling relationship, especially in the areas of rivalry and jealousy. Mitchell (2000, 2003) has written in strong terms of the hatred felt by children at the birth of a sibling. Her view is that the child will feel murderous towards the baby. Coles (2003), whilst agreeing with this, thinks that there are more benign feelings too. Rustin (2007) is more of this view, and writes of both the difficulties and the gains of having a sibling. The writings of Dunn (1984), Dunn and Kendrick (1982) and Bank and Kahn (1982) both offer broader views of siblings and their relationships, all of which point to complexity and the mixed feelings of love and hate.

On the surface, the evidence in my study of the psychological impact on the sibling donors confirms the findings of the literature already reviewed. Such findings have been evident since the 1980s. It may be that because the overall numbers of sibling donors are relatively small, the recommendations for further study and attention have in many ways gone unheeded. However, in this study I have used psychoanalytic theories to endeavour to understand in more depth why there was such a profound impact on the siblings who donated their marrow.

'The psychological mechanisms of projection and introjection have their analogy in the physical processes of expelling and taking in' (Waddell 1998:213). This mechanism is present from birth, and is how the newborn copes with the psychological shock of separate life outside the womb. The hunger pains experienced by the baby can be felt as an attack by the breast (or bottle).

Movement in the bowel or gut can also be experienced by the infant as terrifying, since he or she does not know when it will end. Bion (1962) further developed this Kleinian theory and suggested that the good enough 'containing' mother might digest these difficult experiences, as it were, and return them to the infant in a more manageable form. This process of ridding ourselves of unpleasant or uncomfortable feelings continues throughout life, in different forms and also with different intensities.

My findings can be understood as suggesting that the process of bone marrow donation can be experienced as a concrete form of projective identification, especially during adolescence, when sexual feelings and emotions are more volatile. The most vivid and painful example of this is Tariq's accusations against Farah. As seen in the previous chapter, Farah's family did not discuss his physical responses to the GvHD, and Farah was left alone with her sense of having given her brother something toxic. The literature about sibling bone marrow donors does address the sense of responsibility felt by donor siblings – Weaver et al. (2015:2) comment that 'donors carry a sense of guilt' – but I am attempting to understand the fantasy behind this reaction.

Medical staff could quite easily explain the reasons for physical reactions. My nurse colleague who described how a donor might watch 'you going into her' was accurate. But the unconscious meaning had a more complex connotation for the adolescent donor. As already stated, the sibling relationship is complex, comprising love and hate (not always in equal measure). Thus the fantasy may be that not only is the marrow being transferred but something else is being transferred along with it, such as passionate feelings of love, hate and rivalry, especially when an ill sibling has absorbed much of the parents' attention.

Henningsen (1980) described her work with a sibling donor aged five years. This child had become distressed after the donation, and Henningsen felt that 'the operation and donor situation mobilised unconscious fears of death as well as phantasies of poisoning viz a viz the sister' (Henningsen 1980:37). This was a young child, and the fantasies were explained through her play. However, we know that although these sorts of overt fantasies become more private or unconscious, they will still be present as children grow and develop. Klein (1989:80) writes of puberty that 'there are points of similarity with the analysis of

the small child, owing to the fact that at the age of puberty, we once again meet with a greater dominance of the instinctual impulses and the unconscious, and a much richer phantasy life.' Klein notes that during puberty or adolescence there is a return to earlier states of mind as the young person separates from the parents. Adolescents are in many senses driven by instinct and desire. This return to a 'richer phantasy life' is very familiar in work with adolescents.

Alby (1990:78) wrote of the impact of sibling bone marrow donation from the perspective of the recipient: 'transplantation can lead to the risk of feeling oneself transformed, even taken over by the donor.' Whilst this is from an adult perspective and from a recipient, it highlights the power of such a medical procedure, which involves the transfer of a bodily fluid containing what can feel like the concrete substance of who you are.

A blog on the website for the Anthony Nolan Trust contains a frank account by Nicky, a recipient of an unrelated donation. Nicky is clear that she is very grateful for the life-saving marrow, but she also explains how difficult she found it to receive both a stranger's blood and also bone marrow from an unrelated donor: 'I really struggled with the idea of a blood transfusion, someone else's blood. It made me feel somehow as if I'd be less myself if I had it – because *I am me*' (Nicky 2016). She also says of her transplant: 'I still haven't got over the thought of having someone else's stem cells – on the day, I didn't even want to see them... but there was a deeper feeling, beyond squeamishness; I was worried that I wasn't me anymore.' Nicky is able to articulate her sense of someone else's marrow taking away her sense of self. I wonder if she was afraid that the donor had been projected into her almost concretely, wiping her out.

There is a powerful sense of merging in both Alby and Nicky's accounts.

Parmar et al. (2003) write from the sibling donor perspective, and express a fear (or perhaps an unconscious wish) that the recipient might die from the donor's nut allergy. There is some evidence that allergies may be transferred, so perhaps such fears are not entirely based in fantasy. Hallstrand et al. (2004:3089) state that 'marrow-derived immune cells from allergic donors can transfer the predisposition to allergy and asthma.' The reality of this outcome

may increase the anxiety for sibling donors, who must witness their brother or sister experiencing many or all of these side effects.

Françoise Daune (2014:108) describes her work with adult sibling donors:

‘Certainly, there is a potential sharing of status, but does the question of who is incorporating whom apply? As I have already shown, the donation gives rise to anxieties and fantasies.’ Daune speaks of the sharing of genes vertically (with the parents), but points out that bone marrow donation is horizontal and reveals which of the siblings, if any, share the same genes. In particular she mentions genes that increase the likelihood of breast cancer. Discovering who has these and who has been spared can create strong feelings of hatred and rivalry. It is as if these internal worlds of envy, hatred or rivalry, normally private and only known to ourselves, suddenly become public knowledge in the form of blood results, as with Farah, Tariq and their younger sister.

This question ‘who incorporates whom’ is a powerful one, and links in my mind with projective identification as well as with important questions of identity and separation that are particularly present in adolescence.

Edwards et al. (2006:40) note that ‘siblings and peers are essential in helping us separate from our parents.’ They also comment on their own use of the concepts of projection and projective identification to enable their thinking about adolescents as a group: ‘these concepts also shed light on the group dimensions of sibling dynamics’ (Edwards et al. 2006:41). The authors describe how the denied parts of the self are projected into another person. In an adolescent group, relationships fluctuate continually, and these can be seen as either good or bad parts of the self: ‘It can be equally difficult for a person to own their positive qualities, their assets and talents, because of guilt, fear of envy, retaliation’ (Edwards et al. 2006:42). This may be an explanation for Farah’s failure to obtain the grades she needed to become an engineer. Prior to her final donation Farah felt that she was a good student. But it seems she felt that what she had projected along with her bone marrow was bad, and so in identification with this she became in her words ‘rebellious’ and did not do as well as anticipated. Farah may also have felt that all of the ‘good student’ parts of her had also been projected, lost to her because they now resided in her brother. Farah therefore was left with all the bad or ‘rebellious’ parts of herself.

Edwards et al. (2006:39) write that siblings 'are simultaneously individual and one of a series'. Tammy and John both referred to their recipient sibling in this way, Tammy describing how 'we' were waiting for grommets and John looking ahead to when 'we' would start working, in other words when the bone marrow would begin to engraft. Mitchell (2003:152) writes of the 'seriality' of siblings, but also links this to the thought of the serial killer who murders those he sees as the same, whilst Freud (1955) suggests that there is a dilemma for siblings who wish to belong whilst at the same time yearning to be unique.

In Carson McCullers' novel *The Member of the Wedding* (1946:172), the pubertal Frances cries when her older brother is married and about to leave with his bride: 'You are the we of me, her heart was saying, but she could only say aloud: Take me!' Her brother, now joined to his bride, is no longer part of her, and she feels both rejected and alone. Seen through the lens of all of this literature, the emotional impact of sibling bone marrow donation, especially during adolescence, becomes more complex and more profound.

Thys et al. (2015:279) write that kidney transplants in adults 'generated a special bond between donor and recipient, characterized by gratitude and admiration, but also raised new expectations concerning the recipient's life style.' Whilst this is a different type of transplant and is again reporting the words of adult donors, it implies that some ownership of the donated organ remains, making it important that the recipient treat it well, as though the two bodies are now intimately connected. This is a concrete form of projective identification where the good organ has replaced the diseased one and there is an anxiety that the transplanted organ will be mistreated. Alison was at first rather critical, and indeed a little patronising, about her brother's 'boys' holiday', but then became more thoughtful, and was able to name the feeling of being a 'backup' for him and having to take care of herself. This sense of responsibility whilst at the same time having no control over the use or abuse of her bone marrow was powerful, and might perhaps prove lifelong.

The concept of projective identification enables a deeper understanding of the psychological impact on sibling bone marrow donors, particularly those in their adolescent years as they endeavour to establish a sense of their own identity which will enable them to move towards independence.

This concludes Chapter Five and my identification and explication of the themes that have emerged in my research on the question 'what is the emotional impact on adolescent sibling bone marrow donors?' In Chapter Six I shall discuss how these themes have allowed a greater insight into the emotional impact on adolescent sibling bone marrow donors. I will make recommendations that I hope will improve the service to this group of bone marrow donors. I will also look at where the needs lie in terms of future research.

CHAPTER SIX: RECOMMENDATIONS AND CONCLUSION

6.1 Context and aims of the research

This research study set out to add to and develop the body of available empirical evidence about the psychological impact on adolescents donating bone marrow to their sibling. I have worked since 2003 as a child and adolescent psychotherapist in a large paediatric cancer service, where children and young people from the age of one up to the age of 25 are treated for their disease. This hospital can only offer bone marrow transplants for children above the age of 13, and there are around 20 bone marrow transplants a year. This number is increasing, as conditions other than cancer are being treated with bone marrow transplants. I have seen the profound impact that bone marrow transplants have on these families. When the bone marrow donor is a sibling, the strain on the donor and the family is much greater. There has been a growing concern amongst medical staff, nurses and doctors alike, about sibling bone marrow donors. I have received support, interest and enthusiasm from the medical consultant who first drew my attention to her concerns about this group, as well as from the CNSs who work with these families daily.

I wanted therefore to use my professional training as a child and adolescent psychotherapist to shed new light on the emotional impact on this group of sibling bone marrow donors. The use of psychoanalytic theory allows the investigation of 'below-the-surface feelings', for example in relation to the young woman I referred to in my introduction to this thesis. Whilst her fear was not exactly 'below the surface', I would argue that the meaning of her feeling of being physically diminished may have been linked to her feelings of anger at having to repeat what we know can be a difficult procedure.

I completed all the necessary ethical approvals, and following ethical consent by the Joint Research Office at University College London Hospitals dated 11 August 2011, and with the support of the haematology team, I contacted sibling donors who were about to donate or had already donated. I also contacted donors whose sibling had died during or just after transplant.

As a result I saw five adolescent sibling donors: two boys, both of whom had recently donated, and three girls, who had first donated up to five years ago. They had all been adolescents at the time of their last donation, ranging in age from 13 to 17. I was not successful in recruiting donors whose sibling had died, and I will return to this later in this chapter.

Following this summary of the context and aims of the study, I will now summarise my main findings. I will then make recommendations as to how the psychological support of sibling donors in adolescence might be strengthened. Finally, I will make some concluding comments on the research.

6.2 Summary of main findings

There were four main findings:

1. The eldest three of the five participants were all adamant that they wanted to donate, but for the youngest two the decision was made for them. However, for all the donors there was a sense of 'no choice', as the donation was for a sibling and therefore the desire to donate was bound up with a strong family imperative.
2. The study has discussed the 'qualified' altruism of the donors. This reflects the donors' accounts of expecting some gain for themselves from the donation – for example, gratitude, or a better relationship with the recipient. I have referred to this as "qualified" altruism' to take into account the donation of bone marrow, which offered no physical benefits to the donor – a definition of altruism – whilst at the same time including the dimension of donors wanting or expecting some gain.
3. The third finding was in relation to the short-term physical and emotional impact of donating. I found that there was for all participants some physical pain, discomfort, immediate anxiety or embarrassment. One donor became anaemic for a time after donation.
4. The fourth finding was in relation to the long-term physical and emotional impact. For two of the donors, Farah and Tammy, there was significant emotional impact. For example, Farah felt she had caused her brother harm when he suffered facial GvHD. The other three donors also continued to experience concern or anxiety for their recipient sibling. The use of the psychoanalytic concept of projective identification has enabled

a deeper and important understanding of the processes of this emotional impact.

6.3 Recommendations

1. Transplant teams working with adolescent donors and recipients should include a psychotherapist or a psychoanalytically trained psychologist, who will be aware of unconscious as well as conscious thoughts and feelings in this group of patients at a time when emotional and physical change is at its peak. The psychoanalytic concept of projective identification offers a powerful way of understanding the process of the impact in relation to bone marrow transplant, and enables a greater understanding of the complex sibling relationship, particularly in relation to the donation of bone marrow as a body fluid. A psychotherapist or psychologist who is integrated into the transplant team will then be a part of the family's psychological preparation for what is a complex procedure for both recipient and sibling donor.
2. Sibling donors should be seen before donation and offered follow-up appointments as standard practice, so that this is seen as part of the procedure and is therefore more acceptable to the sibling donors.
3. Sibling donors who have already donated should be invited to discuss what would have been helpful, physically and emotionally, both prior to and after their donation. A leaflet could then be produced with their participation and agreement, and made available to future sibling donors. The group discussion would also be a way of allowing the donors to speak of their experiences, and this could be beneficial for them.
4. Similarly, parents who have supported children through a bone marrow transplant should be invited to contribute to the preparation of information on donation that would include a section referring to the use of a sibling donor. I would strongly recommend that this should address some of the complex feelings experienced by sibling donors.
5. I have stated in this study that none of the donors who donated to a sibling who subsequently died responded to my request to join the study. Whilst I cannot be sure, it may be that these siblings did not wish to return to the hospital (although I offered to see participants in their homes) or that they did not wish to expose themselves or their families to

their grief if interviewed at home. They may have felt as if they were responsible for their sibling's death, which would have made a research interview difficult to attend. There is some support for this in the literature (Weaver et al. 2015:3).

Switzer et al. (1998) suggested that for adult sibling donors there was some relief if the recipient sibling died. This may have been due to the fact that the bereaved donors no longer had to witness their sibling's slow and sometimes turbulent recovery. It may follow, then, that adolescent sibling donors might also feel a sense of relief when a very ill sibling dies, but this could leave them with further guilt and perhaps a belief that no one would accept this feeling. Rowe (2007:195) addresses this difficulty: 'There is the exultation at having won the competition to be good, rapidly followed by the guilt of having thought such a wicked thing.'

Since I was unable to interview any of the bereaved donors, this remains speculation. However, if a psychotherapist or psychologist was present in the transplant team and was able to offer follow-up appointments, a relationship with the donor would be established, making it easier to offer support to these young people.

Thus my recommendation here is that there should be a psychoanalytically trained psychotherapist or psychologist present in transplant teams to address these concerns for adolescent donors and recipients. The interviews and analysis discussed in this thesis reveal the complexity of using siblings as bone marrow donors, especially during their adolescent years, when emotional and physical change is at its height.

The challenge remains of how to design empirical work to explore the experiences of donors whose recipient sibling has died. If sibling donors were to meet the psychotherapist or psychologist before being tested as a possible match or before they donated to their sibling it may be easier for them to return for support if their recipient sibling died. However it may then not be ethical or advisable to request that this be a part of a research project. However because adolescent sibling donors will remain small in numbers it may be possible to make links with other transplant

teams in the country to enable a larger research project that would enhance our understanding of this group.

6.4 Conclusion

This is a small-scale study, although the interviews and analysis were conducted in great depth and detail. How confident can one be that the findings are reliable? The sibling donors who participated came to tell me their stories, which I felt they did with honesty and openness. Their descriptions are consistent with my clinical experience and that of my colleagues in the psycho-oncology team. The emotions that are generated in young people and their families in a cancer service are a result of the close connection between physical illness and disfigurement and the powerful psychological impact that this engenders.

Alvarez (1992) writes about projective identification and how a person may feel as if they have lost a part of themselves to someone else, particularly when it is a part of themselves that they valued, as in Farah's case. Alvarez (1992:81) recognises that the patient needs to reintroject the 'lost part', but also writes that they need to 'explore' it in order to allow the 'thought to become thinkable'. In other words, had Farah had some support and space to think about what she was feeling, she might not have 'rebelled' to obtain the attention she needed.

Each of the donors on the surface was well; however, all displayed anxieties and feelings about their donation. The presence of a psychotherapist or psychoanalytically trained psychologist within transplant teams would enable the conscious and unconscious concerns of adolescent sibling donors to be thought about, as Alvarez (1992) suggests.

Hobson (2009:xv) writes about the value of a child psychotherapist undertaking a research project:

To register, contain and understand such experiences – and to convey that understanding in an appropriate form – is to provide something that is not merely humane and deeply valuable in itself, but also a means to promote the children's mental integration.

I have also argued that my role as a child psychotherapist, with my capacity to look beneath the surface, extended my understanding of the position of

adolescent sibling bone marrow donors, and removed some of what Weaver et al. (2015:3) describe as 'a screen or block between the viewer and the form'. The importance of a psychotherapist or psychologist working alongside the medical teams in such work should be seen as fundamental.

Balbernie (2003) writes of research he undertook where he had an established prior relationship with his participants. This he argued was helpful in creating a sense of trust and avoiding 'social distance' (Balbernie 2003:397). Whilst I did not know all the participants, I was very much seen as a part of the haematology team. This I believe allowed the participants and their families to have that sense of trust in the study, as I understood what families had had to endure during treatment. It may have made it possible, for example, for Farah's mother to persuade her to join the study, as it was being conducted within the hospital where she had donated.

The five sibling donors who generously donated their stories have enabled me to understand more about the emotional impact of giving bone marrow to a sibling. As the ability to treat more diseases with bone marrow transplants increases, so the use of sibling donors may also increase. It is vital that donors be offered the support they deserve, especially during adolescence.

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APPENDIX ONE



APPLICATION TO REGISTER FOR A RESEARCH DEGREE PROGRAMME

(TO BE COMPLETED BY THE PROPOSED SUPERVISORY TEAM AND THE STUDENT)

In completing this form you should refer to the relevant sections of the Research Degree Regulations (Part 9 of the UEL Manual of General Regulations) and the UEL Code of Practice for Postgraduate Research Programmes.

This form should be typewritten wherever possible.

Confirmation of registration will be sent to the student's and the Director of Studies' UEL email address.

When fully completed, this form must be submitted to the nominated individual in the School - usually the Research Administrator or Officer to the SRDSC, accompanied by Form SDN for each supervisor nominated.

1. STUDENT'S DETAILS

FULL NAME	Mrs Jane Elfer			
UEL STUDENT NUMBER	9506577			
PROGRAMME FOR WHICH YOU ARE CURRENTLY ENROLLED <i>(Please Tick)</i>	MPHIL		PHD (EUR)	
	PHD VIA MPHIL		PROF DOC	*
	PHD DIRECT		MPHIL BY PUBLICATIO N	
	PHD BY			

	PUBLICATION			
TITLE OF PROFESSIONAL DOCTORATE PROGRAMME (IF APPLICABLE)				
DATE OF FIRST ENROLMENT FOR CURRENT PROGRAMME	September 2009			
CURRENT MODE OF STUDY (Please Tick)	FULL TIME		PART TIME	*
NUMBER OF MODULES CURRENTLY REGISTERED FOR (For Professional Doctorates only)				
REQUESTED DATE FOR START OF REGISTRATION (For MPhil/PhD only. Registration must occur within 6/12 months of the date of enrolment for FT/PT students respectively and may be backdated to that date)	January 2011			
DECLARATION OF PREVIOUS REGISTRATION. For MPhil/PhD only, if you have a previous period of registration elsewhere which you wish to transfer and to form part of your registration at UEL, please give the dates and location of this registration. Proof of this period of registration must be provided.	N/A			

I AM PART OF THE CHILD AND ADOLESCENT PSYCHOLOGICAL MEDICINE TEAM AT UCLH AND HAVE THE AGREEMENT AND SUPPORT OF THE BONE MARROW TRANSPLANT TEAM.

2. THE PROGRAMME OF RESEARCH

PROPOSED TITLE OF THESIS

TO INVESTIGATE THE EMOTIONAL IMPACT OF ADOLESCENT SIBLING BONE MARROW DONATION

AIM OF THE INVESTIGATION

- 1. TO EXPLORE THE LONG TERM EMOTIONAL IMPACT OF BONE MARROW DONATION ON THE DONOR;**
- 2. TO IDENTIFY WHETHER EMOTIONAL SUPPORT FOR DONORS INFLUENCES THE EMOTIONAL IMPACT OF DONATION;**
- 3. TO MAKE RECOMMENDATIONS FOR ADOLESCENT TRANSPLANT TEAMS FOR THE CARE OF SIBLING DONORS.**

DETAILS OF YOUR PROPOSED RESEARCH IN LAY TERMS

TO INVESTIGATE USING SOME QUESTIONNAIRES AND REGULAR INTERVIEWS HOW SIBLINGS FEEL ABOUT DONATING BONE MARROW TO AN UNWELL BROTHER OR SISTER AND HOW MUCH THESE FEELINGS ARE AFFECTED BY THE OUTCOMES OF TREATMENT. TREATMENT IS NOT ALWAYS SUCCESSFUL BUT EVEN IF IT IS THERE IS SOME EVIDENCE THAT THIS ALTRUISTIC ACT DOES HAVE AN EMOTIONAL IMPACT ON THE DONOR AND THAT HAVING AN UNWELL SIBLING DOES AFFECT ACADEMIC ACHIEVEMENTS AND SOCIAL RELATIONSHIPS.

PROPOSED PLAN OF WORK, INCLUDING ITS RELATIONSHIP TO PREVIOUS WORK, MAXIMUM 4,000 WORDS FOR MPhil/PhD STUDENTS, MAXIMUM 2,000 WORDS FOR PROFESSIONAL DOCTORATE STUDENTS. *Please include in your discussion a description of the research methodologies and explain why these methodologies are the most appropriate for the task. Include a list of references for all works cited. Gantt charts may be used.*

In order to understand how donors are affected by donation to a sibling the Child Psychotherapist would initially invite all the families who face the prospect of [bone marrow] transplant to join the study. These families will be those who are being treated within the Teenage Cancer Service at University College London Hospital. Generally these young people will have Leukaemia

or Aplastic Anaemia.

A description and the reasons for the study would be given to the families. Permission and agreements to join the study would be sought from the adolescent tissue donors and from parents or guardians. Given the very difficult nature of the illnesses and treatments it would be important to approach families with the utmost care and sensitivity and to be prepared for families to decline to join the study. It would be made clear to all families that they would be free to withdraw at any point during the study. If this was to happen it would not affect the family's right to access psychological help from the service available to all families of adolescent patients at UCLH.

Part A

The Child Psychotherapist [researcher] will begin the study by joining the transplant team in clinic in order to meet the families and to introduce the study and the Psychological service which is offered to all families in the Teenage Cancer Unit. An outline of the study would be offered to families in the days before they undergo tests for compatibility. Those families for whom a sibling match is found would be approached again with a request to join the study. All families regardless of donor match would be offered support by the Child Psychotherapist or another member of the Child and Adolescent Psychological Medicine service.

If none of the patient's siblings was found to be a match the family would be offered support during their treatment at the hospital in the same way all families can access psychological help.

The parents of the patient whose sibling is a match would be asked to complete a '**Strengths and Difficulties**' '**CRIES**', **CGAS** and '**Honosca**' questionnaires (these questionnaires are standardised and validated assessment instruments). This would give insight into the ordinary resiliencies of the family members. It would provide some understanding of how the donor was functioning at home, school and in their social life. These questionnaires would be analysed according to guidance provided with these tools but would also be used in conjunction with the recorded interviews with the donors.

All family members, including the patient, would be interviewed individually by an experienced Child Psychotherapist in order to understand more about the family and their feelings about the transplant. In all cases confidentiality would be strictly observed. The option to withdraw would remain the same. The sibling donor who has agreed to join the study would then meet with the Child Psychotherapist on a regular basis. The interviews would be audio taped and employ a psychosocial methodology (Hollway and Jefferson 2000). Analysis would look for common themes in the donor's responses to being a Bone Marrow donor for their sibling.

Interviews with the donor would be carried out after compatibility tests had done and the donor informed. With their permission a series of regular meetings at three month intervals would be arranged over the next two years. These would be recorded as described above. If the donor and Child Psychotherapist felt that it would be helpful to continue to meet after the time limits of the study this would be arranged between the donor and therapist in the way that the Psychological Medicine team would offer for any of its patients.

The parents of the donor would also be interviewed at similar time points in order to understand from them whether they feel donation has a particular impact on this child. These ideas and impressions will be compared to that of the donor's interviews as current research would indicate that the siblings of child who is seriously ill often do not show their anxieties to already stressed or anxious parents. The research mentioned in this proposal shows that the impact on siblings 'is profound and worthy of further study'.

Finally it would be important also to interview the siblings who are not a match and to record their thoughts and feelings about this in a separate interview and again some three months to assess whether this too has an impact.

The number of sibling matched transplants here at UCLH is between two and five each year so that the target number of participants will be between eight and ten and the time for this study is two years.

Part B

Since the number of bone marrow transplants in the Teenage Cancer Unit is relatively small permission to interview previous sibling donors will also be sought from families whether the donation was successful or not and with their permission to meet with them up to three times to gain some insight into their experience. This would have to be done with the utmost care for the feelings of the families involved especially those whose children have died.

Families would be sent a carefully designed letter explaining the reasons for the study and the request for their help. Separate permission slips would be written for this group.

Once again if families felt that they would like some emotional support but did not wish to join the study this would be provided by the Psychological Medicine Team in the usual way. Requests for support are often received after the patient has finished treatment when they have more time to reflect on their experiences. Child Psychotherapists at UCLH also offer continued support to families who have been bereaved or can find alternative support locally if this is requested by the family.

There are currently about sixteen families who have been had transplants since the new Teenage Unit was opened in 2005. It is hoped that at least half of this group in other words eight families could be prepared to join this retrospective study.

The method used would be similar to that used with the families currently in treatment with the exception of the questionnaire tools which would no longer be valid due to the retrospective aspect of these interviews. However detailed recordings would be made of interviews and an analysis of those made as with currently treated families to see if there are any common themes.

Child Psychotherapy

Child Psychotherapists work with children throughout the country in a variety of settings including Child and Adolescent mental health teams. They are trained to work with children of all ages with a variety of difficulties. Within the hospital setting they are working with children and their families who are affected by the event of illness or accident. These events are usually traumatic and challenge the most stable of families. Child Psychotherapists are familiar with the impact of trauma. They are trained to work with the utmost sensitivity in these situations and yet also offer patients the opportunity to speak of matters that perhaps they feel unable to else where. This provides an important outlet for otherwise unbearable emotions.

Literature Review

It will be important for this thesis to look not only at the literature concerning Bone Marrow Transplant donation but also that which looks at the impact generally on children who have a chronically ill sibling. Psychoanalytic theory and literature will I hope add an extra layer to my thinking about sibling relationships. There are few studies concerning the impact on sibling donors and in most they are concerned with the more general impact on the family as a whole than on the donor in particular.

Henningsen and Ludwig-Maximilians (1980) wrote of their work with a five year old bone marrow donor. They describe the impact that the donation had had on this little girl and in their conclusion recommended that donors and their parents should receive psychotherapy during the procedure. This of course as a single case study but is nevertheless interesting as it highlights the fantasies of a small child and her preoccupation with death and poisoning both of her and her recipient sister (Pot-Mees and Carien 1987)

Danion-Grilliat (1994) noted that the sibling donors in their study had 'identity problems and identification conflicts on the part of the donor along with the reactivation of previously unconscious sibling rivalry'. It is also noted that there were indications of clinical symptoms in donor that was indicative of their

'psychic suffering'

In a more recent paper Gurpreet Parmar, now a medical student reflects on his own experience of donating Bone Marrow to his brother (Parmer, Wu and Wah Chan 2003). He writes of his terror of the procedure but also of the disruption to his family. He and his co authors recommend more attention and support be offered to sibling donors and that further studies be undertaken to understand the emotional impact on children. Finally, a study of sibling distress during Bone Marrow transplant concluded that distress could be limited by parents sharing the care given to the child who is unwell (Hinds, Pelletier, Alderfer, Davis and Penz 2012). They note that the whole family is affected when a child has a diagnosis of cancer. They quote 28-81% of siblings display behavioural difficulties.

There is a wide variety of writing on the impact of having a sibling who is unwell, for example a systematic literature review (author 2009) notes that more attention should be paid to the siblings of cancer patients as the impact on all aspects of their lives is profound. I would also like to include in my study some of the Psychoanalytic thinking about sibling relationships which I hope will enrich the understanding of these familial relationships, for example Mitchell (2000), writes about her sense that the primary emotion felt by siblings for one another is murderous. By contrast, Coles (2003) is much more inclined to feel that there are positive gains from having siblings as well as having the more ordinary feelings of jealousy.

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SUMMARY OF THE ELEMENTS OF THE INVESTIGATION THAT ARE NOVEL, ORIGINAL OR CREATIVE AND THAT MAY CONSTITUTE PRODUCTION OF ORIGINAL KNOWLEDGE OR AN ORIGINAL INTERPRETATION OF EXISTING KNOWLEDGE

CURRENTLY THERE IS LIMITED UNDERSTANDING OF THE EMOTIONAL IMPACT ON SIBLING DONORS BUT THESE DO SEEM TO POINT TO A NEED FOR A MORE DETAILED STUDY OF SIBLINGS THOUGHTS AND FEELINGS ABOUT DONATION. AS A CHILD PSYCHOTHERAPIST I HOPE TO BE ABLE TO OFFER GREATER INSIGHT INTO THE FEELINGS OF THIS GROUP OF YOUNG PEOPLE AND FROM THAT BE ABLE TO RECOMMEND NEW WAYS IN WHICH TO SUPPORT THEM.

A HEALTH AND SAFETY RISK ASSESSMENT IS REQUIRED IN RESPECT OF ALL PROPOSED LABORATORY EXPERIMENTS AND/OR FIELDWORK.

DOES THIS INVESTIGATION REQUIRE LABORATORY EXPERIMENTS AND/OR FIELDWORK? (Please Tick)	Yes		No	*
IF YES, A MANDATORY COPY OF THE RISK ASSESSMENT, SIGNED BY THE STUDENT AND THE DIRECTOR OF STUDIES, IS ATTACHED (Please Tick)	Yes		No	
DOES THE PROGRAMME OF RESEARCH INVOLVE WORK THAT WOULD REQUIRE THE APPROVAL	Yes		No	

OF THE UNIVERSITY'S ETHICS COMMITTEE PRIOR TO THAT PART OF THE PROJECT COMMENCING? <i>(Please Tick)</i>				
IF YES, HAS A FORM FOR APPROVAL ALREADY BEEN MADE TO THE UNIVERSITY'S ETHICS COMMITTEE? <i>(Please Tick)</i> <i>You may not proceed with this part of your research until approval has been granted.</i>	YES		No	
WILL THE PROGRAMME OF RESEARCH LEAD TO OUTPUT(S) WHICH WILL HAVE COMMERCIAL FORM(S) AND/OR INTELLECTUAL PROPERTY OF POTENTIAL VALUE? <i>If yes, you must inform the Knowledge Transfer Office</i>	YES		No	*

3. PROPOSED SUPERVISORY TEAM

Form SDN - Nomination as a Supervisor/Director of Studies should be appended for the Director of Studies and each supervisor nominated. The SRDSC will use information supplied about current and past supervisions to ensure that this proposal does not breach the maximum number of PGR students that can be supervised without consent.

NOMINATION OF DIRECTOR OF STUDIES	
NAME AND TITLE	Dr Anthony Lee

SCHOOL	Tavistock Centre, 120 Belsize Lane, London NW3 5BA			
EMAIL ADDRESS (preferably an institutional or official email address)	TLee@tavi-port.nhs.uk			
HOLDS A PHD/PROFESSIONAL DOCTORATE? (Please Tick)	YES	*	No	

NOMINATION OF SECOND SUPERVISOR				
NAME AND TITLE	Mr Ricky Emanuel			
SCHOOL (and for supervisors external to UEL, their institution and full postal address)	Department of Child and Adolescent Psychiatry Royal Free Hospital, Pond Street, London NW3 2QG			
EMAIL ADDRESS (preferably an institutional or official email address)	Ricky.emanuel@royalfree.nhs.uk			
HOLDS A PHD/PROFESSIONAL DOCTORATE? (Please Tick)	YES		No	*
NOMINATION OF THIRD SUPERVISOR (IF APPLICABLE)				
NAME AND TITLE				
SCHOOL (and for supervisors external to UEL, their institution and full postal address)				
EMAIL ADDRESS (preferably an				

<i>institutional or official email address)</i>				
HOLDS A PHD/PROFESSIONAL DOCTORATE? <i>(Please Tick)</i>	YES		No	

OVERALL SUPERVISORY EXPERIENCE AND ACTIVITY OF THE PROPOSED SUPERVISORY TEAM				
NUMBER OF RESEARCH DEGREE STUDENTS CURRENTLY SUPERVISED <i>(excluding this one)</i>	MPhil		PROFESSIONAL DOCTORATE	
	PhD <i>including PhD (Eur)</i>			
NUMBER OF RESEARCH DEGREE STUDENTS PREVIOUSLY SUCCESSFULLY SUPERVISED TO COMPLETION FOR	MPhil		PROFESSIONAL DOCTORATE	
	PhD <i>including PhD (Eur)</i>			
IF THE COMBINED EXPERIENCE AND ACTIVITY OF THE PROPOSED SUPERVISORY TEAM DOES NOT MEET THE REQUIREMENTS STIPULATED IN UEL'S RESEARCH DEGREE REGULATIONS, PLEASE PROVIDE A SHORT STATEMENT JUSTIFYING WHY CONSENT IS SOUGHT AND WHY THIS PARTICULAR SUPERVISORY TEAM IS MOST SUITABLE FOR THE PROGRAMME OF RESEARCH.				

4. NOMINATION OF ADVISORS

NOMINATION OF FIRST ADVISOR, IF APPLICABLE	
NAME AND TITLE	
CURRENT POSITION, DEPARTMENT AND INSTITUTION	
FULL POSTAL ADDRESS	
EMAIL ADDRESS (preferably an institutional or official email address)	
PREVIOUS POSTS HELD	
QUALIFICATIONS	
NOMINATION OF SECOND ADVISOR, IF APPLICABLE	
NAME AND TITLE	
CURRENT POSITION, DEPARTMENT AND INSTITUTION	
FULL POSTAL ADDRESS	
EMAIL ADDRESS (preferably an institutional or official email address)	
PREVIOUS POSTS HELD	

QUALIFICATIONS

5. STUDENT'S DECLARATION

PLEASE NOTE THAT ELECTRONIC SIGNATURES ARE NOT ACCEPTABLE

I CONFIRM	
<ul style="list-style-type: none"> • THAT I WISH TO APPLY TO BE REGISTERED AS A STUDENT FOR THE POSTGRADUATE RESEARCH AWARD INDICATED AT THE HEAD OF THIS FORM. • THAT THE PARTICULARS GIVEN IN THIS FORM ARE CORRECT. • THAT EXCEPT WITH THE SPECIFIC PERMISSION OF THE RESEARCH DEGREES SUBCOMMITTEE, ANY WRITTEN COMPONENT OF THE PROGRAMME MUST BE SUBMITTED IN ENGLISH AND I MUST ALSO UNDERTAKE AN ORAL EXAMINATION IN ENGLISH. • ELECTRONIC SIGNATURES ARE NOT ACCEPTABLE 	
STUDENT	SIGNED: JANE ELFER
	DATE: 25/11/2010

6. SUPERVISORY TEAM'S DECLARATION

PLEASE NOTE THAT ELECTRONIC SIGNATURES ARE NOT ACCEPTABLE

WE CONFIRM
<ul style="list-style-type: none"> • THAT WE SUPPORT THIS FORM AND BELIEVE THAT THE STUDENT HAS THE POTENTIAL TO COMPLETE THE PROGRAMME OF WORK PROPOSED • THAT, AS REQUIRED BY OUR UNIVERSITY'S RESEARCH DEGREE REGULATIONS, WE ARE NOT OURSELVES CURRENTLY RECEIVING SUPERVISION ON A RESEARCH DEGREE PROGRAMME AT ANY HEI • THAT, IF APPLICABLE, WE AGREE TO THE REQUEST FOR THE BACKDATING OF REGISTRATION

WE RECOMMEND THAT THE APPLICANT BE REGISTERED FOR A RESEARCH DEGREE		
DIRECTOR OF STUDIES	SIGNED:	
	PRINTED:	DATE:
SECOND SUPERVISOR	SIGNED:	
	PRINTED:	DATE:
THIRD SUPERVISOR (IF APPLICABLE)	SIGNED:	
	PRINTED:	DATE:

8. DEAN OF SCHOOL'S DECLARATION

PLEASE NOTE THAT ELECTRONIC SIGNATURES ARE NOT ACCEPTABLE

I CONFIRM THAT THE UNIVERSITY AND SCHOOL FACILITIES AND RESOURCES DETAILED IN THIS FORM, TOGETHER WITH OTHER APPROPRIATE RESOURCES, SUCH AS SUPERVISOR(S)' TIME, WILL BE AVAILABLE FOR THE DURATION OF THE PROGRAMME OF RESEARCH		
DEAN OF SCHOOL (or nominee)	SIGNED:	
	PRINTED:	DATE:

9. DOCUMENT LOG

ONCE SECTIONS 1-8 HAVE BEEN COMPLETED, THIS FORM, ALONG WITH FORM(S) SDN, SHOULD BE SUBMITTED TO THE RELEVANT SCHOOL SRDSC FOR CONSIDERATION AND THE REFERENCE FOR THE PERTINENT MINUTE(S) RECORDED BELOW. IF RECOMMENDED, THE FORM AND FORM(S) SHOULD THEN BE SENT TO THE RESEARCH DEGREES SUBCOMMITTEE FOR APPROVAL ALONG WITH THE RELEVANT EXTRACT FROM THE MINUTES (EITHER ATTACHED TO THIS FORM OR PASTED AT ITS END). PLEASE NOTE

THAT THE FORM WILL NOT BE PROCESSED UNTIL THE GRADUATE SCHOOL HAS RECEIVED THE MINUTES OF BOTH COMMITTEES IN THEIR ENTIRETY.

RECOMMENDED SCHOOL SRDSC	BY	DATE OF SRDSC:
	MINUTE REF:	
APPROVED BY RESEARCH DEGREES SUBCOMMITTEE	DATE OF RESEARCH DEGREES SUBCOMMITTEE:	
	MINUTE REF:	

Appendix Two

APPENDIX TWO



University College London Hospitals **NHS**
NHS Foundation Trust

Joint Research Office

Office Location:
1st Floor Maple House
149 Tottenham Court Road
London W1T 7DN

Postal Address:
UCL,
Gower Street
London WC1E 6BT

Tel No. 0845 1555 000 ext 9995 Fax No 0207 380 9937
Web-sites: www.uclh.nhs.uk; www.ucl.ac.uk

FINAL R&D APPROVAL

10/10/2011

Mrs Jane Elfer
University College London Hospitals NHS Foundation Trust
Teenage Cancer Unit
University College Hospital
250 Euston Road
London
NW1 2PG
UK

Dear Mrs Jane Elfer ,

Project ID: 11/0188 (Please quote in all correspondence)
REC Ref: 11/LO/0560
Title: The emotional impact on sibling bone marrow donors

Thank you for registering the above study with the UCL/UCLH/RF Joint Research Office (UCLH Site). I am pleased to inform you that your study now has local R&D approval to proceed and recruit participants at University College London Hospitals NHS Foundation Trust.

Please note that all documents received have been reviewed and this approval is granted on the basis of the key documents provided which are ethically approved by the Research Ethics Committee:

Document	Date
REC approval and approved documents	11/08/2011

As Chief/Principal Investigator you are required to ensure that your study is conducted in accordance with the Department of Health's Research Governance Framework for Health and Social Care (2nd edition 2005) and that all members of the research team are aware of their responsibilities under the Framework.

This R&D approval is conditional upon you complying with all requirements of the Research Ethics Committee notice of favourable opinion.

Please find attached the conditions of the R&D approval and a reminder of your responsibilities as a researcher and ensure that both yourself and the research team are familiar with and understand the roles and responsibilities both as a team and individually.



UCL Hospitals is an NHS Foundation Trust comprising: The Eastman Dental Hospital, The Heart Hospital, Hospital for Tropical Diseases, National Hospital for Neurology and Neurosurgery, The Royal London Hospital for Integrated Medicine and University College Hospital (incorporating the former Middlesex and Elizabeth Garrett Anderson Hospitals).

Please do not hesitate to contact a member of the team with regards to assistance and guidance for your research.

Yours sincerely

PP P.D. ✓

Professor Monty Mythen
Director of Research and Development
UCL/UCLH/Royal Free Joint Research Office



UCL Hospitals is an NHS Foundation Trust comprising: The Eastman Dental Hospital, The Heart Hospital, Hospital for Tropical Diseases, National Hospital for Neurology and Neurosurgery, The Royal London Hospital for Integrated Medicine and University College Hospital (incorporating the former Middlesex and Elizabeth Garrett Anderson Hospitals).

